Designing and Developing an Early Identification and Early Intervention Program for children who are deaf and hard of hearing in the Gaza Strip

by

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#### Abstract

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- Designing and Developing an Early Identification and Early Intervention Program for children who are deaf and hard of hearing in the Gaza Strip.

Thesis directed by, Dr. Brenda Schick.

The Gaza Strip is one of the most poor and highly populated areas in the world. It also has one of the highest numbers of disabilities, including deaf and hard of hearing. The services that are provided to the DHH population in Gaza are restricted to identifying the hearing loss and the fitting of hearing aids. Young children who are identified as DHH will not receive any other services until they are 4 years old, at this age they will be enrolled in the kindergarten and school programs. As a result, the idea of establishing and early intervention program in the Gaza Strip will be very helpful to the DHH and their families, especially with the developments of the early identification techniques that are taking place in Gaza nowadays. The early intervention program that will be serving the DHH children and their families will be a leading program that will be modeled by all the DHH habilitation/rehabilitation organizations in Gaza. It will be the model that fits Gaza following some of the infrastructure details of the early intervention programs in 7 states in the United States of America. Mainly the Gaza program will follow the lead of the Colorado Home Intervention Program. Some changes are made on the program to fit the needs of the DHH in the Gaza Strip, those changes are very important to increase the effectiveness and functionality of the Gaza Program.

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#### Chapter I

#### Introduction

#### **Purpose of the Study**

The Gaza Strip is one of the highly populated and poor areas in the world due to the political disputes that have been taking place there for centuries. The dense population and the poor life have resulted in a noticeable increase of the number of disabled people. This is true for people with hearing loss, as the number of children who are born with hearing loss exceeds 1 for every 100 newborn. This makes the need for services for the Deaf and Hard of Hearing (DHH) people very important since they represent a big number in the community. As a result, projects of early identification of hearing loss are taking place in the Gaza Strip now; however, early identified children with hearing loss don't receive any services except for the amplification. They and their families have to wait tell the child is 4 years old to be enrolled in the school system for DHH children. This makes it difficult for those children and for their families to catch up with the language that is needed for the school and for communication in general. Therefore, the aim of this study is to design an early intervention program for the Gaza Strip that will provide services to the DHH children and their families.

#### **Scope of the Study**

Since early identification and early intervention is being legislated in the USA and they are functional at almost all the states, through this study data is going to be collected about the early intervention programs in the United States. The design principles and experiences should be inspired from the collected data to be used in putting together the pieces that are needed to design a suitable function program for the Gaza Strip. The information that will be collected is going to be manipulated and changed in a way to fit the situation in the Gaza Strip, and finally an early intervention program will be designed to be implemented in Gaza to serve the DHH children and their families.

#### **Data Limitation:**

The data that is going to be collected is going to be in English. This requires translation it into Arabic to be suitable for the situation in the Gaza Strip. In addition, information is going to be restricted to the situation in the USA which is totally different than the situation in the Gaza Strip. As a result this will make the need for change some of the fundamental aspects of some programs very necessary.

#### Chapter II.

#### **Early Identification:**

The Implementation of early identification of hearing loss is steadily improving. It has accelerated approximately over the last 10 years (Garvel, Berg, Bradley, Cacace, Campbell, Dazell, Decristofaro, Greenber, Gross, Orlando, Pinheiro, Regan, Spirak, Stevens, & Preive, 2000). Until recently, the average age of identifying hearing loss in children remained about at 30 months (Harrison & Roush, 1996; JCIH, 2000).Children with a less severe hearing loss were identified at the age of 3-4 years old and those with a unilateral or a high frequency hearing loss were identified at the age of 5-6 years old (Elssmann, Matkin& Sabo, 1987). Late identification is also common for other countries. For example, Bamford and Davis (1998) reported that 24% of children with permanent hearing loss in the UK were not identified until they are 3.5 years old (3.5 or 3 years 6 months?). There have been some attempts to develop techniques of early identification to make it possible to detect hearing loss with children who are less than the previously mentioned ages, however, they had not shown much change until the early 1990s,when significant progress was made in reducing the average age at which a permanent hearing loss is identified (Mauk & White, 1995). This was due to the lack of advanced technology and systematic hearing screening programs. With the development of more rapid and accurate means of screening, the average age of identification is reduced and the outcomes are resulting in a much younger population that needs the attention of hearing loss habilitation professionals.

Newborn hearing screening programs are being mandated in 39 states in the USA and many other states have pending legislation (Rabbitt-Park, 2003). Also it is spreading in other countries and been used as a powerful tool in association with early intervention in deaf and hard of hearing habilitation (Yoshinaga-Itano, 2002).

#### Legislation of early Identification:

Many studies have focused on the importance of the early identification of hearing loss on the development of the early identified child and examined the positive effects on language and speech (Bubbico, Di Castelbinco, Tangucci, Salvinell(2007), Vohr, et, al., (2008), Yoshinaga-Itano, et. al. (1996) and Yoshinaga-Itano, Sedey, Coulte, and Mehl(1998). In light of the fast development of the UNHS programs and the results of the implementation of those programs, in addition to the advanced technology, everybody rushed to support the UNHS, as newborn hearing screening initially became a focus of state legislation beginning in the 1970s, with legislation targeted at high risk populations (e.g. children in the neonatal intensive care unit). More recently, state legislation requiring the hearing screening of all babies, also known as universal newborn hearing screening. The concept of UNHS was formally endorsed by the National Institutes of Health Consensus Development Conference Statement in 1993 and by the Joint Committee on Infant Hearing (JCIH) in a 1994 Position Statement. Hawaii and Rhode Island were the first states to pass UNHS legislation in the early 1990s. By 2005, a total of 37 states had passed UNHS legislation either requiring or strongly encouraging hearing screening of newborn infants. In addition, even those states without legislation have programs in place to coordinate and promote UNHS and related services, Denise et al. (2007).

#### **Importance of Early Identification:**

Early identification of hearing loss is considered to be the first step in detecting a hearing problem. The factors that make early identification of hearing loss an important and needed step in deaf and hard of hearing habilitation is that the hearing loss occurs

more than any other birth defect. Northern and Downs, (2000) indicated that the prevalence of newborn and infant hearing loss was estimated at 1.5 to 6 per 1000 live births in the USA. Mehl and Thomson (1998) compared the prevalence of newborn and infant diseases to hearing loss and they found that the hearing loss prevalence is higher, as other diseases occur at any rate between 0.3 to 50 in 100,000 live births while hearing loss occurs in 260 live births per 100,000. If conductive and unilateral hearing losses are included, the number would rise considerably. On the other hand, not all hearing losses will show at birth, such as progressive hearing losses and hearing losses among infants and young children (Fortnum, Sumerfield, Marshall, Davis, & Bamford, 2001). Following the previously mentioned data, the prevalence of hearing loss is frequent enough to justify launching universal Newborn Hearing Screening Thompson, et.al., (2001), White K. (1997).

Yet, there is more data supporting the need for early identification in the literature apart from the high incidence of hearing loss. Late detected hearing loss has serious developmental consequences. Hearing loss causes more difficulties on the individual, both socially, and economically and for the family and society in productivity and social life (Mauk& White, 1995; Carney & Moeller, 1998.). The Gallaudet University annual survey (2010) showed that children with severe to profound bilateral losses demonstrate substantial deficits in reading comprehension. When these children are 8 years of age, they are already almost 1-1/2 years behind their peers. That gap continues to widen over time, with the average deaf and hard of hearing (DHH) child or youth never exceeding a grade equivalent of 4 years, in spite of the fact that most of them are enrolled in educational programs specifically designed for DHH students. Of course, most of these children did not have the benefit of very early identification (Schildroth & Karchmer, 1986). Although virtually everyone agrees that severe to profound bilateral hearing loss has substantial negative consequences for all aspects of academic performance, the consequences of mild bilateral or unilateral hearing loss are less well known. There are, however, a number of studies demonstrate that even mild or unilateral sensorineural hearing loss has substantial negative consequences.

It is also clear that early childhood hearing loss causes speech and language delays in development of early receptive and expressive vocabulary in young children with hearing loss, in a study of 168 children by (Mayne, Yoshinaga-Itano,& Sedey, 2000) They used maternal report measure MacArthur-Bates Communicative Development Inventory to examine vocabulary size at 8 to 22 months of age. Compared with normative data of normal hearing children, the study showed that children who are at the 50<sup>%</sup> percentile for hearing loss (average performers) are significantly delayed in both receptive and expressive vocabulary in comparison with normal hearing children. Those children showed acceleration of expressive vocabulary learning after 25 months of age which is approximately 7 months later than their normal hearing peers.

Through the previously mentioned studies, the relationship between hearing impairment at an early age and delayed speech and language skills is well established.

However, research also shows that early identification of hearing loss helps reduce speech and language delays in children with hearing loss (Robinshaw(1994), Yoshinaga-Itano, Sedey, (2001), Yoshinaga-Itano, Sedey, Apuzzo, Carey, Day, & Coulter, (1996). For example, Robinshaw(1994) studied 5 young children with severe to profound hearing loss who were identified with hearing loss between 3 to 5 months old. All of them were fitted with hearing aids by the age of 6 months. This group of children was compared to a 5 normally hearing control children and to previous data on 12 children with severe and profound hearing loss, whose hearing loss was confirmed on an average age of 2 years and 3 moths. She found out that the early identified children acquired vocal communication and language skills at approximately the same age to the 5 normally hearing control children and before the deaf children who were late identified. The author did not report scores or define approximate. The study suggested that early identification followed by amplification leads to a better language acquisition and development.

Similarly, Yoshinaga-Itano, Sedey, Coulte, and Mehl(1998), compared 72 deaf or hard of hearing children whose hearing loss was identified before the age of 6 months to 78 children whose hearing loss was identified after the age of 6 months, it was found that children whose their hearing losses were identified by the age of 6 months showed a clearly better language scores than children whose their hearing losses were identified after the age of 6 months. Language Quotients (LQs) were used to examine the participants' language abilities. Children with hearing losses identified by 6 months of age had significantly higher, receptive, expressive and total language (LQs) than those whose hearing losses were identified after 6 months of age. The early identified children had adjusted mean LQs of 79.6 (SD=25.8) for receptive language and 78.3 (SD=26.8) for expressive language and 79.0 (SD=25.6) for total language. Late identified children had adjusted mean LQs for receptive language of 64.6 (SD=20.9) and for expressive language of 63.1(SD=19.8) and for total language of 63.8 (SD=19.3). For the children who had normal cognitive abilities, the language advantage that was found in the study was found across all test ages, communication modes, degrees of hearing loss, and socioeconomic strata. It also was not affected by the minority status, gender and the presence or absence of additional disabilities. Studies continue to support the early identification of hearing loss as, Yoshinaga-Itano. (1996) compared language abilities of hearing-impaired children identified before 6 months of age (n = 46) with similar children identified after 6 months of age (n = 63). All children had bilateral hearing loss ranging from mild to profound and normally-hearing parents. Language abilities measured by parent report using the Minnesota Child Development Inventory (expressive and comprehension scales) and the MacArthur Communicative Developmental Inventories (vocabulary). Cross-sectional assessment with children categorized in 4 different age groups. The results showed a difference in the comprehension and receptive language abilities and the vocabulary size of the children Identified before 6 months of age. Vocabulary size and expressive language did not differ in the 13-18 months old children in both groups, the difference started to be clear after 2 years of age.

Even children with unilateral hearing loss demonstrate developmental delays. In a study comparing 5 children with a unilateral hearing loss to children with normal hearing, the results showed that the children with unilateral hearing loss lag behind the children with normal hearing in their performance in math, language and social functioning in approximately 1-1/2 years for a 10 years old child (White, 1997). In addition Teele, Klein, Chase, Menyuk, Rosner, and the Greater Boston Otitis media Study Group(1990) found out in their study of 207 children who were selected randomly from a cohort of 498 followed respectively from birth until the age of 7 years, that middle ear disease in the first three years of life is associated with significantly lower scores in mathematics and reading. Similar differences were found for articulation and use of morphologic markers. The Wechsler Intelligence Scale for Children - Revised test was administered. After considering time spent with Middle Ear Effusion (MEE) during the first 3 years of life, time spent with MEE after age 3 years was not a significant predictor of scores on WISC-R IQ test, the Goldman-Firstoe and the Goldman-Firitoe, Woodcock tests, the "WUG" (Berko-Gleason) test, and the Peabody Picture Vocabulary test for speech and language abilities.

However, a study on middle ear status was done on 65 healthy new born Dutch children showed fewer effects Zumach, Gerrits, Chenault, Anteunis, (2010).The children's clinical reports were reviewed every 3 months after the first 2 years of age; language comprehension and production were evaluated at 27 months and again at 7 years. Children at the age of 2 years who went through middle ear infection episodes showed delay in language comprehension and production. Those results could not be established at school age. This study indicates that the effect of otitis media hearing loss on language comprehension and development in clear at the early years of life (birth to 2), however, the effect starts fading away when the child grows up.

To connect early identification to better outcomes in early intervention, Vohr, Jodoin-Krauzyk, Tucker, Johnson, Topol & Ahlgren, (2008), conducted a longitudinal study of the outcomes of a cohort of 30 infants identified in the Rhode Island universal newborn hearing screening program and 96 hearing control subjects. Eligible families with children with all degrees of congenital hearing loss were invited to enroll. Child language skills were assessed by using the MacArthur-Bates Communicative Development Inventory, Words and Gestures, at 12 to 16 months. They found that it is important for children with hearing loss to be identified as early as possible, as very early enrollment (</=3 months) in early intervention had beneficial effects on early language for children with hearing loss. Using the CDI test, children with hearing loss who started early intervention services by 3 months of age showed more-advanced receptive and expressive language development as early as 12 to 16 months. Separate analyses demonstrated differential effects of early intervention for the children with mild/minimal hearing loss (later gestures, total gestures and a trend for early gestures) and those with moderate/profound hearing loss (words produced and early gestures).

In examining within group effects of early intervention enrollment, it is of interest that words produced (either signed or spoken) and early prelinguistic communicative gestures were affected by early intervention more in the moderate/profound hearing loss group. These infants participated more frequently in early intervention and, because of their degree of hearing loss, might have derived greater benefit from early intervention focused on establishing effective referential communication, such as searching for items, pointing to pictures, looking to speakers with the use of suitable amplification. Children in the mild/minimal hearing loss group had greater benefit in all types of gestures. Later gestures include more symbolic play activity, including pretend play and imitating, which may be associated with more-advanced language skills.

In a study that was completed in Italy by Bubbico, Di Castelbinco, Tangucci, Salvinell, (2007), 70 children with congenital prelingual deafness were divided into 2 groups based on their age at the start of the intervention program: 17 children enrolled between 0-12 months of age, and 53 children enrolled after the age of 12 months. The age of intervention is defined as the identification and confirmation of hearing loss, hearing aids fitting, and enrollment in the early intervention program. Assessments were carried out at 5 years of age. Receptive language abilities were measured using the Peabody Picture Vocabulary Test (PPVT), while the cognitive abilities were assessed using the Raven Standard Progressive Matrices test. The language and cognitive score tests (PPVT) of samples of children with hearing loss was compared with normal standardized scores of hearing peers at 5 years of age. A progressive decline in the mean PPVT score with increasing ages of enrollment was found. The mean receptive language score of the children enrolled within the first 12 months was significantly better compared to those

over 13 months. The nonverbal IQ, showed no statistically significant differences in IQ scores between children with early and late age of enrollment. Data revealed that language abilities are significantly affected by the degree of hearing loss .Children with severe hearing loss, had lower language abilities than children with moderate hearing loss.

The early identification of prelingual hearing loss at birth through the neonatal screening must therefore be considered an essential first step in a quality intervention program. The results of the previously discussed studies indicate that the early identification of hearing loss is an important step towards improving the language abilities of the DHH children. In most cases (DHH) children succeed to catch up with their speech and language within the normal level. However, early identification is important; but it has to be followed by suitable amplification and enrollment in an early intervention program. Children who fail to be enrolled in an early intervention program will not gain the benefit of the early identification and will continue facing challenges in their life and school development. As a result, early identification, amplification and early intervention should be dealt with as one unit; none of them could succeed by itself.

# The effect of early identification on families

Little attention was paid to the effect of early identification of hearing loss on parents of the deaf and hard of hearing early identified children. Young and Tattersal (2007) performed a study on 45 parents/caregivers (representing 27 families) whose infants were correctly identified as deaf or hard of hearing during the first phase of the implementation of the national universal Newborn Hearing Screening Program in the U.K. The average age of the children when parents were interviewed was 25 weeks. The results showed unlimited support of the parents for the early identification program as 21 parents out of the 27 indicated that it was good to know that their children had a hearing problem early and it is a good thing to start working with the problem as early as possible regardless the shock they went through for the first couple of weeks after the results were confirmed. However they also reported the psychological complexities by recognizing both the grief and reassurance that early knowledge brings. There appears to be some risks of early knowledge-inducing timetables of expectations that create distress when not met speedily. Parents knew the developmental advantages of early identification are underpinned by notions of normal speech and the possibility of their children to be like hearing children. Some parents indicated that they could not enjoy the parent child relationship and the early development of their child as much as parents of normal hearing children when they found out that the child had a hearing problem. Logically, the first several months of the child's life are important for the parents, especially new parents to enjoy having a new baby and the joy associated with it. Parents of a late identified child might be expecting that their child has a problem after noticing the behaviors and the development of their child. The effect of knowing that their child has a hearing problem might be less severe because they suspected that their child was not developing typically. On the other hand, the parents of the early identified DHH children, especially if the identification takes place at the first couple of months of the

child's age, might experience a psychological impact, because they did not expect it and they did not have any signs to make them ready for the news.

Parents who suspect that their children has a hearing problem, then confirmed through the screening, could accept it more and their children could benefit from the early identification and early language input, (Thompson, MacPhilips, Davis, Homer & Helfand, 2001). Following the previously mentioned studies, it is my understanding that parents who suspected a problem and it was not confirmed by the screening and then it would be confirmed later, will have more stress and their children will not benefit from the early identification and intervention as been reported by Quittner, Alexandra, Steck, Julie, Thompson, Rouiller, Rebecca, (1991). In addition, Meadow-Orlans (1994) studied 20 mothers and 16 fathers whose infants' hearing losses were diagnosed very early (mean age = 2.8 months) and comparable parents whose infants are hearing. Parenting stress of mothers and fathers whose infants were deaf was no greater than that of parents of normal hearing infants and comparable to norms for the Parenting Stress Index. Social support was associated with lower levels of parenting stress for hearing mothers and fathers of deaf infants, but not for parents who had a hearing loss. These results help to confirm the importance of early diagnosis and intervention for parents as well as for their children.

As a result, it is important to work fast and effectively with the parents of the newly detected children, and enroll them in an early intervention program where they receive the needed support and their child receives the needed intervention and therapy. The results of the early identification and intervention and their impact on the child and the family will be the best support to the parents.

#### Early identification in the Gaza Strip:

Following the previously mentioned data, it is important to start a UNHS in the Gaza Strip to indentify the deaf and hard of hearing children as early as possible, for the early intervention program to be effective and to start working with the children as early as possible for better results in the Gaza Strip. Historically, there have been attempts to start a UNHS but the program was not supported by the government and has been the responsibility of the Non-Governmental Organizations (NGOs), which required lots of effort and financial resources that they don't have. The Atfaluna Society for the Deaf Children (2010), Atfaluna news (www.atfaluna.net) has received funds to start a newborn hearing screening program at the Primary Health Care Units of the United Nations Work and Relief Agency (UNRWA) in the refugee camps. The program is for 3 years and it is aiming to screen the hearing of all the newborns before 6 months old. If this program shows reliable results, it is going to produce a large number of children with hearing loss due to different reasons, mainly conductive hearing loss due to middle ear dysfunction (Atfaluna, 2010). This will require all the efforts towards building an early intervention program and a follow up system that guarantees the enrollment of all identified children in a follow up and early intervention program.

#### **Early intervention:**

Early Intervention is a coordinated and comprehensive system of programs, services, and resources that are designed to meet the physical, intellectual, language, speech, social and emotional needs of children from birth to three years who have been identified as having a developmental delay or who are at risk for developing a delay. In the USA the Early Intervention system of services is provided under Part C of the Individuals with Disabilities Education Act (IDEA). This federal law requires states to develop coordinated programs of Early Intervention services for children with disabilities from birth to age three years and to ensure that the children and their parents have the same legal right to a free and appropriate public education (FAPE) as children that do not have disabilities.

Early Intervention services provide families with the information and support they need to maximize their child's overall development. Early Intervention services from qualified, experienced professionals can help parents of DHH children understand their child's hearing loss. The program will help parents also to learn about their child's strengths and needs and ways to help the child to develop. Through the program they will discover that they and their family play an important role in the child's development. Parents are their children's teachers. The early intervention programs usually trust parents' decisions and give them the right to choose what is best for their children. Parents are the experts in making decisions for the benefit of their children. As a result, it is important to find a program to follow up the children who are early identified. Such a

program is crucial for the child and the parents since it provides them with the needed tools to overcome the hearing loss, partially if not completely. Recent research supports the fact that any early identification program should be followed by an early intervention program. Children who are identified with a hearing impairment early in their life and are not enrolled in an early intervention program will not have the chance to catch up with their hearing pears.

#### **Importance of early intervention:**

Results of recent studies provide strong evidence of the benefits of early identification and intervention (prior to 12 months) on the development of language and communication skills (Apuzzo and Yoshinaga-Itano, 1995; Calderon & Naidu (1998); Moeller, 1998; Robinshaw, 1995; strong, Clark, Johnson, et al., 1994; Yoshinaga-Itano and Apuzzo, 1998a, 1998b; Yoshinaga-Itano, Sedey, Coulter, and Mehl, 1998). Out of those studies the study of Yoshinaga Itano et al. (1998) conducted several studies comparing groups of children identified and provided intervention between 6 and 12 months with those identified and provided intervention at later ages. Findings have generally been consistent in demonstrating that those children identified and provided intervention by 6 to 12 months obtained significantly better language scores than children identified after 12 months, as measures by Minnesota Child Development Inventory (MCDI) Irenton and Thwiing, 1974). On average, the earlier identified children demonstrated near normal rates of language skills. Apparently, a group of the DHH showed scores at the lower 25% of normal language skills, throughout the assessment period, whereas the late identified children with hearing loss demonstrated the typical delay of deaf and hard of hearing (assessment age ranged from 13 to 40 months). I meant in this paragraph to show that Early Identification should be followed by Early Intervention or otherwise it will be meaningless.

One popular early intervention program in the USA is the SKI\*HI, (10 years, a historical perspective (2010) http://www.aahbei.org/files/forms/Ten.pdf). A study of this program was conducted on 2768 children from the SKI\*HI early intervention project at the age of 36 months at the time of post testing. Using pre, post and predicted test scores for early language development (SKI\*HI Language Development Scale) Strong, Clark, Johnson, et al. (1994) found that, on average, the children progressed in language skills at the rate of one month for every month enrolled in intervention. Those children who enrolled at a very early age actually gained the most.

Calderon and Naidu (1998) studied the effect of early intervention on the speech and language of 80 children (43 female, 37 male). Age of intervention was collapsed into three groups with an age range of 12 months in each group. 9 children entered early intervention before 12.5 months of age (group 1), 39 entered between 12.6 and 24.5 months (group 2), and 32 were 24.6 or older when entering (group 3). Results showed that the expressive and receptive language skills of the children who entered early intervention at young ages (group one) had made more progress at the discharge from the early intervention program than the skills of (group 2 and 3).

Ramkalawan, and Davis, (1992) found significant correlations between the language measures and age of intervention of a group of children between 27 to 80 months old who had a sensorineural hearing loss ranging from 32 dB to 98 dB in the better ear. In addition, Musselman, Wilson, and Lindsay, P. (1988) found that the age of intervention is effective in increasing the receptive language skills of the deaf and hard of hearing children in their longitudinal study of 118 children between the ages 3 to 5 years old. The results were significant at the first year of age but the correlation between the age of intervention and the oral language skills faded after the first year of intervention. Musselman, in this study attributed the reduction in the effect of the early intervention on the oral language skills of their sample to the age of children. They reported that the effect might be clearer if the sample was younger. Greenberg, et. al., (1984), reported findings on an independent evaluation of an early intervention program for severely and profoundly deaf children located in Vancouver, British Columbia, this comprehensive program served families with children under age 3. Their findings showed that children who were enrolled in an intervention program showed significantly better communication skills than children who were not enrolled in any program.

Researchers always try to find solutions for the limitations that are caused by any disability. Since hearing loss is considered to be a disability in the hearing community, researchers have tried to find ways and techniques to help deaf and hard of hearing children to overcome the delays they are facing due to their disability, one important element in helping those children to develop is to provide them with a suitable mode of

communication that can be doable and functional in their community. In addition to the early identification of hearing loss and the new technology of CI and digital hearing aids and the large assortment of assistive listening devices, many studies were done to try to improve the fact that early intervention is as crucial as early identification and amplification fitting.

Moeller, (2000) studied the effect of early intervention on language development on DHH children. She found out that there is a significant and systematic decline in the mean vocabulary standard score with increasing ages of enrollment. A negative correlation was found between the vocabulary size and the age of enrollment of 5 years old, however, there has been a strong correlation between the early enrollment in an early intervention program and the vocabulary size. Yoshinaga-Itano (2003) summarized the developmental outcomes of Colorado children with significant hearing loss. Some of the research compares children born in hospitals that have implemented universal newborn hearing screening programs for newborns. Other research compares the developmental outcomes of children who have been early-identified with hearing loss. Earlyidentification is defined as identification of hearing loss within the first six months of life. Late identification in the Colorado studies is defined as age of identification of hearing loss after the age of six months. In a few of the studies, age at initiation of intervention was used. Within the Colorado system, age of identification can be interpreted as almost synonymous with age of intervention, as the vast majority of children enter intervention services with two months after the identification of the hearing loss. Children who were

early-identified and had early initiation of intervention services (within the first year of life) had significantly better vocabulary, general language abilities, speech intelligibility and phoneme repertoires, syntax as measured by mean length of utterance, socialemotional development, parental bonding, and parental grief resolution. Two other studies (Nebraska and Washington state) of early- versus later-initiation of intervention services report findings similar to the Colorado studies. Direct comparisons with the historical literature are not possible because the developmental delays of what would now be termed "later-identified" were too great to report. As most DHH children were identified way later than 6 months of age. As a result, it is not correct to compare nowadays results with the old results of older children.

It is crucial to mention the benefit of the use of sign language with young children who are identified with hearing loss as early as possible. Sign language could be used at anytime, especially at the transitional time between identification and enrollment in the early intervention program. Studies show that learning sign language has a positive effect on young deaf children's spoken language skills (Preisler, Tvingstedt, & Ahlstrom, 2002; Schlesinger & Meadow, 1972; Yoshinaga-Itano & Sedey, 2000). One of these studies evaluates childhood cochlear implants. Over a two-year period, Preisler et al. (2002) studied the patterns of communication of 22 pre-school children who had received cochlear implants between the ages of two and five. This research took place in Sweden, where parents are required to establish some sign language communication with their child in order for the child to be considered for a cochlear implant (Swedish National Board of Health & Welfare, 2000). Preisler et al. concluded that the children who developed the most spoken language also had well-developed signed language skills. Although signed language by itself did not guarantee the development of spoken language, those children who had insufficient, or discontinued, signed language development also had very little, or no, spoken language abilities. It was also observed that when children with little signed language improved their signed language abilities, their spoken language also increased (Preisler et al., 2002).

Preisler and Ahlstrom (1997) found that the use of signed language positively affects language development and social and emotional development among pre-school hard of hearing children. The children in their study were bilingual in spoken Swedish and Swedish sign language, and they exhibited flexibility in their use of the two languages. These children used patterned and purposeful code switching to match the requirements of their communication partners. In addition, the communicative context of this study is mirrored in other studies of young bilingual hearing children who show differential and appropriate use of their developing languages (e.g., Genesee, Nicoladis, & Paradis, 1995; Comeau, Genesee & Lapaquette, 2003 Proficiency in ASL, as well as positively influencing spoken language development, has been shown empirically to support English literacy in deaf students (Hoffmeister, 2000; Padden & Ramsey, 1998, 2000; Singleton et al., 1998; Strong & Prinz, 1997, 2000). This body of research, which shows a positive correlation between high levels of ASL proficiency and English literacy skills, is also supported by earlier literature that demonstrates that native ASL users have

somewhat higher English literacy abilities than deaf children who learn ASL later in life (Israelite & Ewoldt, 1992).

Since the early use of sing language could help in improving the spoken language abilities and skills, any successful early intervention program should use sign language as one of their main elements throughout the program and should for sure include a training pattern for the parents to gain the needed knowledge of sign language to be able to use it with their children.

Yoshinaga-Itano and Sedey (2000) investigated the relationship between speech development and various demographic and developmental factors, including mode of communication, in children aged 14 to 60 months. The researchers found that expressive signed and spoken language ability was a significant predictor of speech development in young deaf and hard-of-hearing children. While access to a signed language is thought to increase overall linguistic ability in deaf children, it has been clearly shown to increase vocabulary levels (Anderson, 2006; Watkins, Pittman & Walden, 1998).

In a review of some studies to investigate the relationship between language competence and speech perception abilities in DHH children Blamey (2003) in his study made a link between high-level linguistic competence and speech perception ability in DHH children with hearing aids and cochlear implants. He reviewed studies that compare the speech perception ability of deafened adults with those of deaf and hard-of-hearing children; the scores are lower for children than for deafened adults, even among children who have more residual hearing (e.g., Blamey et al., 2001). In order for deaf and hard-

of-hearing children who have hearing aids and cochlear implants to comprehend spoken language input, an advanced knowledge of phonology, syntax, and semantics is needed (Blamey, 2003).

# **Best practices for the Gaza Strip**

The situation in the Gaza Strip requires a very attentive effort to establish a sustainable early intervention program. The program should be serving the DHH children and their families under the social rules that govern life in the strip. Such a program should guarantee the best services in addition to the needed community support. Since it is recommended through most of the studies reviewed previously that it is better that all infants be screened for hearing loss within the first six months of their lives, receive diagnostic audiological assessment, and be enrolled in early intervention services immediately after complete diagnoses. The best practice that will fit the Gaza strip should be a joint early identification and intervention program. As a result of the conflicts that are present now, no legislation could mandate any laws regarding early identification and intervention of disability in the Gaza Strip. Therefore, Awareness should be the way of launching an early identification program of hearing loss. Once such a program is launched, identified infants should need an early intervention program to be enrolled into. The program should guarantee the following:

## Early Intervention (EI) for children with hearing loss should be family focused:

Families have access to EI services provided by specialist(s) with specific training in working with birth-to-three year olds with hearing loss, in addition to other specialists that may be needed (e.g., physical therapists, speech/language pathologists).

- Families may access these specialized services via a variety of supports including outreach by specialized program staff and outreach by other families.
- Services are provided and resources are available in the family's chosen method of communication and educational approach. Since the advances technology of hearing devices such as cochlear implants and digital hearing aids with the various assistive listening devices such as FM systems is not available, total communication will be recommended all the time for children with hearing loss greater than moderately severe (50-70 dBHL).
- During the early period of information gathering and decision making, families are assisted by a person who can present and discuss unbiased information about communication options, respects family choices, and allows parents to make an informed final decision.
- Care focuses on family strengths and follows the family's vision and priorities.
- Services include all members of the family and their circle of support, as requested by the family.
- Care is developmentally appropriate for the child.

- Families, EI providers, and the child's medical home collaborated to provide the child with hearing loss complete access to communication with the important people in their lives ("relationship-focused EI").
- Families choose where to meet with EI providers.
- Brothers and sisters of children with hearing loss have access to age appropriate information, support and instruction.
- Children with hearing loss and their hearing siblings have opportunities to interact socially with other siblings of deaf and hard of hearing (DHH) children, young children, youth, and adults who are DHH.

# EI providers and other professionals working with this population have specialized expertise and training:

- Family resource specialist with initial contact to families have specialized training in effective practices for infants/toddlers who are DHH and related family issues. They provide support and information in an unbiased manner.
- Early intervention providers working with DHH children and their families receive initial and ongoing training in DHH education, child development, early childhood education, and technology.
- EI specialists who are trained to work with children who are D/HH (including consultants who are deaf) participate in outreach to, and consultation with other EI providers and medical professionals.

Families with DHH children enrolled in EI receive appropriate information, evaluation, services, and support. Components include:

- Information about family networking and support services, including support in dealing with the emotional impact of diagnosis (i.e. parent support groups, individual and family counseling).
- Information regarding communication options for DHH individuals, Deaf Culture, and available specialized services and assistive technology.
- Support and careful assistance in exploring and selecting a communication approach, recognizing that this choice may change over time.
- Variety of support models for children/families in learning the communication approach of their choice.
- Ongoing audiological services and monitoring of hearing aids/cochlear implants if requested by parents.
- Assistance in helping the child learn to effectively wear and/or use assistive devices, and to develop his/her residual hearing if requested by parents.
- Opportunities to gain support and information from a variety of individuals who are DHH, and other parents of children with hearing loss (e.g., parent mentoring program).

## Family specialists Meetings and Ongoing Evaluation of Child:

- Participants in the meetings will include, but are not be limited to, family members, EI provider specializing in DHH, audiologist, and any other healthcare/service provider requested by the family.
- The EI team administers and coordinates regular assessments appropriate for children with hearing loss to document progress of child toward developmental milestones and meetings outcomes.

### Early intervention in the Gaza Strip

In 1990, the Sunday Care Center in the Gaza Strip started an early intervention program funded by the USAID using the SKI\*HI program that was translated into Arabic with no changes to the normative data. The program was a very good start with some changes to some of the protocols, especially the word lists and sign language items. This program served almost 105 deaf and hard of hearing; age 3-7 at their homes since it worked with the earliest identified children with hearing loss. Early identification of hearing loss was not effective at that time due to lack of resources. The program lasted for 5 years then it stopped due to lack of funds. That was the only real early intervention program that took place in the Gaza Strip.

In the recent years there have been several attempts to start a comprehensive early intervention program with the advanced early identification equipment and expertise. Children with hearing loss are being identified as early as 1 month old and the number of cases with hearing loss who are less than three years old is increasing with no intervention plans. The available programs are actually a small attempt to serve those children but it is not exceeding 20 families all over the Gaza Strip. There are more than 250 families who need a comprehensive intervention program.

The only work that is done comprehensively with young children is the preschool program at the three schools for the deaf in Jabalya (Jabalya Rehabilitation Society) which covers the northern area of the Strip, (Atfaluna Society for Deaf Children) which covers the middle area and (Al Amal Society) which covers the southern part of the Strip. The preschool programs at those three schools work with children from 3-5 years old. Children come to the school 5 days a week for 6 hours and they learn sign language with some total communication. Their teachers are mostly deaf with a hearing supervisor working with each group. Those programs help in setting some basis for the children to get ready for school, however, the programs don't work directly with the families. Sign language courses are available for the families but they are optional.

A big issue faces the workers at the preschool programs is to convince the families to learn sign language. Parents usually have high expectations for their children to develop spoken Arabic and will start putting pressure on the teachers to stop signing to their children. On very rare occasions, such as when the family has previous incidences of hearing loss and have experienced the use of different option other than sign language but it didn't work, parents will agree to learn sign language and they will not use it at home. It also gets complicated when it comes to educated parents who have access to the internet and other resources. They become so obsessed with the technology and will
sometimes stop sending their children to school hoping to find a donor for a cochlear implant or a digital hearing aid with an FM system.

People who can afford to pay for the advanced hearing devices will go for it and then will start sending their children to regular schools. Deaf and hard of hearing children at regular schools will not perform well, especially with the crowded classrooms that are not acoustically suitable for children with hearing aids. In addition, teachers at the regular classrooms are not qualified to deal with children with hearing loss and the ministry of education doesn't have any audiologists or speech therapists in the system. Moreover, the problem of lack of resources and expertise that could work with the advanced hearing devices is really essential. Gaza has been under closure and siege for the last 5 years. This closure resulted in difficulties in travelling for education and training, in addition to not allowing the specialized organizations in the field of DHH habilitation and rehabilitation to import technology from abroad. International organizations such as UNRWA, USAID, International Welfare, Care International, help in keeping the basic supplies like hearing aids batteries, analog hearing aids and hearing testing equipment available and reachable. The lack of resources cause the DHH rehabilitation organizations to work with the basic available resources and keep the services at the limitation level. As a result, sign language is very important for DHH children and their families to be the basic communication tool.

An early intervention program in the Gaza Strip is a dire need; however, there is a great need for an awareness campaign to go along with it to gain the community support.

It is impossible for it to succeed if it doesn't gain the community trust. In addition, there is a need to start raising funds for advanced hearing technologies such as digital hearing aids, cochlear implants and assistive listening devices.

#### Goals for this project

Since the Gaza Strip is one of the most populated and poor areas in the world, the number of children born with disabilities is one of the highest amongst the third world countries. Children who are born with a hearing problem receive no services until they are age 3-5 years old. Lately, in 2005 some organizations who are working with deaf people started to have the technology and the expertise to perform hearing evaluations on new born children. The number of detected children under the age of 6 months is increasing, they will receive amplification systems (mainly regular analog hearing aids) and then they will stay at home tell they are 3 years old or more. An early intervention program is badly needed in the Gaza Strip, as a result the goals of this project is to:

- 1- Establish a realistic and functional early intervention program to work with the deaf and hard of hearing children and their families.
- 2- Establish functional means to increase awareness and community support for the early identification and intervention program.
- 3- Start a university training program to train early intervention providers.
- 4- Training professionals on new hearing technologies such as CI and digital hearing aids, and advanced assistive listening devices.

- 5- Increase the opportunities of the families and specialists to interact more for the benefit of the child.
- 6- Build a reference website for the families and the professionals as a resource of information.
- 7- Establish cooperation channels with other early intervention programs in the region.

#### **Chapter III.**

# **Background Information about the Gaza Strip:**

#### Geography:

The Gaza Strip is located in the Middle East. It has a 51 kilometers (32 mi) border with Israel, and an 11 km border with Egypt, near the city of Rafah, the southernmost city. Khan Younis located 7 kilometers (4 mi) northeast of Rafah, and several towns around Dair Al Balah are located along the coast between it and Gaza City. Beit Lahia and Beit Hanoun are located to the north and northeast of Gaza City, respectively. Those cities, camps and villages used to be spread out and there used to be vast agricultural areas between them. Nowadays, due to the rapid increase in the population, cities, camps and villages are overpopulated, which led to building residences on the agricultural lands.

Gaza strip has a temperate climate, with mild winters, and humid, hot summers subject to drought. The terrain is flat or rolling, with dunes near the coast. Natural resources include arable land (about a third of the strip is irrigated), and recently discovered natural gas. Environmental issues include desertification, increased salinity of fresh water, sewage treatment, water-borne diseases, soil degradation, and depletion and contamination of underground water resources.

#### **Demographics**

In 2007 approximately 1.4 million Palestinians lived in the Gaza Strip, of whom almost 1.0 million are UN-registered refugees. The majority of the Palestinians are descendants of refugees who were driven from or left their homes during the Arab Israeli War of 1948. The Strip's population has continued to increase since that time, one of the main reasons being a total fertility rate of more than 5.19children per woman (Wikipedia, 2008). In a ranking by total fertility rate, this places Gaza 30th of 222 regions and above all non-African countries except Afghanistan and Yemen. The vast majority of the population is Sunni Muslims, with an estimated 2,000 to 3,000 Christians (Palestinian Central Bureau of Statistics, 2007).

In 2009, 45,000 newborns were born in the Gaza Strip, which is considered to be one of the highest birth rates since the 70s (United Nations for Work and Relief, 2008)

# **Economy:**

The economy of the Gaza Strip is severely limited by high population density, limited land access, strict internal and external security controls, the effects of Israeli military destruction of capital, and restrictions on labor and trade access across the border. Per Capita income was estimated at US\$ 3,100 in 2007, a position of 164th in the world Wikipedia (2008), 80% of the population is below the poverty line according to a 2007 estimation Palestinian Central Bureau of Statistics,(2007). Gaza Strip industries

are generally small family businesses that produce textiles, soap, olive wood carvings, and mother of pearl souvenirs. The Israelis have established some small-scale modern industries in an industrial center. Israel supplies the Gaza Strip with electricity. The main agricultural products are olives, citrus, vegetables, halal beef, and dairy products. Primary exports are citrus and cut flowers, while primary imports are food, consumer goods, and construction materials. The main trade partners of the Gaza Strip are Israel, Egypt, and the West Bank.

Israel's use of comprehensive closures decreased during the period between (1987 to 1997) and, in 1998, Israel implemented new policies to reduce the impact of closures and other security procedures on the movement of Palestinian goods and labor into Israel. These changes fueled an almost three-year-long economic recovery in the Gaza Strip. Recovery ended with the outbreak of the al-Aqsa Intifada in the last quarter of 2000 that lasted until 2004(American Public University, 2010). The al-Aqsa Intifada triggered tight Israeli Defense Forces closures of the border with Israel, as well as frequent curbs on traffic in Palestinian self-rule areas, severely disrupting trade and labor movements. In 2001, and even more severely in early 2002, internal turmoil and Israeli military measures in Palestinian Authority areas resulted in the destruction of capital plant and administrative structure, widespread business closures, and a sharp drop in GDP. During the Intifada, a lot of infrastructure had been destroyed by Israel, such as the Palestine airport. Another major factor has been the decline of income earned due to reduction in the number of Gazans permitted entry to work in Israel. After the Israeli withdrawal from

Gaza, the flow of a limited number of workers into Israel again resumed, although Israel reduced or ended such permits due to the victory of Hamas in the 2006 preliminary elections. Before the second Palestinian uprising broke out in September 2000, around 25,000 workers from the Gaza Strip (about 2% of the population) used to work in Israel every day.

Israel, the United States, Canada, and the European Union have frozen all funds to the Palestinian government after the formation of a Hamas-controlled government after its victory in the 2006 Palestinian Legislative Elections. They view the group as a terrorist organization, and have pressured Hamas to recognize Israel, renounce violence, and agree to past agreements. Since Israel's withdrawal and its subsequent blockade, the gross domestic product of the Gaza Strip has been crippled. The enterprise and industry of the former Jewish industrial villages has been impaired, and the previously established work relationships between Israel and the Gaza Strip have been disrupted. Job opportunities in Israel for Gaza Palestinians have been largely lost. Prior to disengagement, 120,000 Palestinians from Gaza were employed in Israel or in joint projects. Only about 20,000 have been able to keep these jobs.

After the 2006 elections, fighting broke out between Fatah and Hamas, which Hamas won in the Gaza Strip on 14 June 2007. After that, all contact between the outside world and the Strip has been severed by Israel. The only goods permitted into the Strip through the land crossings are goods of a humanitarian nature.

# Health:

A study carried out by Johns Hopkins University (U.S.) and Al–Quds University (in Abu Dis) for CARE International in late 2002 (Care International 2002) revealed very high levels of dietary deficiency among the Palestinian population. The study found that 17.5% of children aged 6–59 months suffered from chronic malnutrition. 53% of women of reproductive age and 44% of children were found to be anemic (as opposed to 37.5% of Israeli woman and 30% of Israeli babies). In the aftermath of the Israeli withdrawal of August and September 2005, the health care system in Gaza continues to face severe challenges. After the Hamas takeover of the Gaza Strip and the subsequent Israeli declaration of Gaza Strip as a "hostile entity", the health conditions in Gaza Strip faces new challenges exacerbated by the intensified Israeli closure. World Health Organization WHO,(2010) expressed its concerns about the consequences of the Palestinian internal political fragmentation; the socioeconomic decline; military actions; and the physical, psychological and economic isolation on the health of the population in Gaza.

Gazans who desire medical care in Israeli hospitals must apply for a medical permit. Permits are not easy to obtain and many sick people don't get permissions and they will be deprived of the medical treatment they need.

The health system in the Gaza Strip is facing lots of challenges due to the closures and siege that causes the hospitals and health centers to face shortages in staff, equipment, and electricity. This leads hospitals to refer patients to hospitals outside Gaza. In the Gaza Strip there are 17 hospitals, 2 of them are children hospitals, one is mental health and one is eye hospital. The other hospitals are small and were established during Al–Aqsa Intifada, the main hospitals in the Gaza Strip are Al Shifa and the European, which include all the specialties and the Ors.

In order to establish a connection between the needs of the Gaza Strip in terms of early intervention, I felt there has been a need to have a closer look at the situation in the Gaza Strip and collect as much data as I could of what services are available for the deaf and hard of hearing children. The result of my study of the situation in the Gaza Strip showed that there are no formal studies or database to derive the information from. This made my search for data difficult and led me to look for informal resources. Due to the political, social and economical status in the Strip, deaf rehabilitation and habilitation are considered to be an accessory. Simply put, the governmental agencies have many other heavy responsibilities. This has led the government to lay the responsibilities of rehabilitation and habilitation of deaf and other disabilities on the Non Governmental Organization (NGOs). Currently most work related to children with hearing loss is conducted by NGOs in conjunction with professionals and citizens of Gaza.

#### **Disability in Gaza:**

Out of the total population of the Gaza Strip, 4% are disabled, almost 70,000 people have a type of disability (NCCR, 2008). The largest number of disabled individuals is the deaf and hard-of-hearing population with estimates as high as 25,000 deaf and hard of hearing people of all ages, representing almost 36% of the total number

of disabilities. This also represents almost 1.5% of the total population of Gaza (Atfaluna 2009).

The disabled people in the Gaza Strip receive their rehabilitation services mostly through specialized NGOs. The government leaves services for disabled to NGOs. Those NGOs receive their funds through international donations and they depend 100% on those donations. When any NGO lacks the funds through the international donations, they will stop its services which results in a reduction or a total cut of some of the services.

The only organization that has the ability to perform hearing evaluations on young children is the biggest organization that is called Atfaluna Society for Deaf Children (www.atfaluna.net). This organization has a well equipped audiology clinic with an ABR unit and portable and diagnostic otoacoustic emission units. All young children who are less than 3 years old are referred to the Atfaluna clinic for early identification.

At the three audiology clinics, deaf and hard of hearing people get fit with hearing aids. The most common hearing aids that are used with the deaf and hard of hearing people are the conventional analog hearing aids. Digital and programmable hearing aids, FM systems, and cochlear implants are not common at all. The number of people who are using this advanced technology is very small and it is estimated that it does not exceed 50 people all over the Gaza Strip (Atfaluna& Al Amal, 2009).

The NGOs are my resource of data as they are the only bodies that are dealing with disability in the Strip. As a result I thought it is important to give an idea about those NGOs and their services. In the Gaza Strip there are 7 NGOs that are working with deaf people, geographically distributed to serve all parts of the Gaza Strip. One NGO (Jabalya Rehabilitation Society) is in the north that covers the northern part of the Gaza Strip. It has a school for the deaf that serves about 150 students of all ages starting at 5 years old to 18 years old, in addition to an audiology clinic. Three other organizations (Atfaluna, National Center for Community Rehabilitation and the Future Society for Deaf Adults) are located in Gaza City, which is considered the biggest city of the strip and the Those two organizations serve deaf people from Gaza City and most populated. neighboring camps and villages. The biggest and most advanced organization is one of the two that are located in Gaza City (Atfaluna) that has a school for the deaf which serves more than 300 deaf and hard of hearing children, starting at 3 years old to 18. In addition, it is the only organization that has the staff and equipment for early identification, and the most advanced audiology clinic in the Gaza Strip. It also provides vocational training and job opportunities for the deaf adults and deaf students who graduate from its school. The second organization (Future Society for Deaf Adults) which is located in Gaza City is specialized in providing services to deaf adults. It is more of psychosocial service organization. In the middle area of the Gaza Strip there are two organizations for the deaf that are serving the one city and 4 camps that are located in the middle of the Strip (Nusirat Rehabilitation Society and Dair Al Balah Rehabilitation Society). Those two organizations provide educational services to deaf children and they are mainly schools for the deaf that serve 300 children altogether from the age of 5 years

old to 18. In the southern part of the Gaza Strip there are two organizations; one is located in Khanunis (Palestinian Red Crescent), which is the second largest city in the Gaza strip. This organization is not specialized in services to the deaf children, it is more of a rehabilitation center for all disabilities including deafness and hard of hearing. It provides miscellaneous services to the deaf people including education and vocational training. The last deaf rehabilitation organization in the Gaza Strip (Al Amal Society) is located on the third biggest city in Gaza which is called Rafah. This organization serves deaf and hard of hearing children from all the southern cities, camps and villages. It has an audiology clinic and a deaf school that serves almost 150 deaf and hard of hearing children ages 5 to 18.

Those are the organizations that provide services to the deaf and hard of hearing children; altogether they serve about 1200 children. The information that I could collect from the records of those organizations indicated that there is a similar number or maybe more of deaf and hard of hearing children who receive no services or are not even detected yet. The dilemma that those organizations are facing is that there is not any national newborn hearing screening program. Most of the deaf children who are identified as deaf or hard of hearing are more than 2 to 3 years old. There aren't any rules for newborn hearing screening; it only depends on the family observations or some referral from private ENT clinics.

Children, who are identified as deaf or hard of hearing in the Gaza Strip, even if they were detected very early, are fit with amplification and sent home with no intervention. None of the previously mentioned schools for the deaf has a specialized early intervention program, however, there has been some tries to follow the SKI\*HI program. However, it did not continue or did not show great success due to the nature of the program that has been developed and established for a different culture and nature of service delivery.



# Map of the Gaza Strip and DHH schools location:

#### Chapter IV

#### **Design Principles for an EDHI Program in Gaza:**

#### **Principles and characteristics:**

The Gaza Strip is over populated, conservative society that is characterized by large families and extended social relationships. In addition to the role of the extended families and the tight traditions that rule the life in the Gaza Strip, there are the Islamic rules that meet with the traditions in many ways. People respect their traditions and the beliefs of their elderly. Relationships at all social levels are ruled by those traditions and anyone overcomes those rules would be odd and could cause him a great deal of difficulty to be accepted in the social system.

Extended families are always ruled by the elderly, usually the oldest man in the family. This man usually plays an important role in all the decisions that should be made by the family and is the one who keeps the family's relationship with other families in a certain shape. It is important that every single person in the family should respect this old man and should listen to what he says even though sometimes it contradicts with what others believe. It is considered rude if somebody opposes the decisions that are made by the leader of the family and this could lead to expel this person of the family meetings and gatherings. As everybody in the family should respect their leader who is usually the oldest, this system applies to all the other family members; everybody should respect the one who is older than him/her. Older brothers and sisters are to be respected by youngsters. However boys consider being the inheritances of the family and are led to

play important roles in all family activities, girls are also to be respected by their younger brothers and sisters. Girls in the families are the future mothers and are going to be leading the families inside the house. Usually the father is responsible for the family needs and position outside the house and the mother is responsible for the family inside the house. Mothers set up the rules inside the house to be followed by everyone. The mothers make sure that everyone completes his/her role. In addition mothers inside the houses take care of all conflicts and try to solve them. Mothers are very respected by everyone at all levels.

Boys are allowed to play outside the house and girls should stay to learn household work. Girls suppose to know how to take care of the house as it is considered to be shameful if a girl gets married while she doesn't know how to cook and to take care of her own house. In addition to the importance of learning the household work, girls should also learn that they should respect the family of their husbands, especially their in laws.

To complete picturing the social life in the Gaza Strip, we have to bear in mind that Islam is the dominant religion in there. More that 98% of the people in the Gaza Strip are Sunni Muslims. Islamic rules in the Strip are not strictly followed as the social traditions are; however, people started getting acquainted with the Islamic rules and they started following some of them. Such as the traditions of how Islam looks to the disability as a test from God or sometimes as a blessing. People believe that their disabled child is given to them as a blessing that tests their patience and respect to God's choice. Complaining is considered to be a blasphemy, and objection to God's well. As a result, people view disability in a different way than in other non Islamic countries; as a Muslim, you have to always to thank God for the good and bad, it's not allowed that you thank God for the good and not accept the bad.

Since Islam doesn't contradict with science, genetic counseling is permitted and people can do it if they have the resources and the ability. Considering the difficult life in Gaza, people do not have the needed resources to go through genetic counseling; however, people who are able to do it get it done abroad. None of the Islamic rules prohibits genetic counseling, however, social rules might. As marriage is a bigger issue that the small family, it is considered to be a strong bond between families. It is a big complicated problem if engaged couple go through genetic counseling and they cannot get married because of positive results. As a result, people avoid going into this issue to keep families relationships within the social structure. In addition, couples cannot go into any testing before they are engaged, and engagement is like marriage, its announced and everybody in the surrounding community will know about it. Therefore, families would feel a shame if this engagement broke due to any reason and everybody will blame the girl and it would be a stigma that might cause her not to get married again.

However, the situation looks complicated; science education increased the awareness of the families regarding having disabled children. Families now refuse to marry their daughters to their cousins, especially if the family had pervious incidences of disabilities. Female education and women awareness helped changing the overall point of view about consequent marriages, adding to it the instructions of Prophet Mohammed who said marrying a stranger would result in healthier children.

Another problem is still in the Gazan community, which is the stigma that follows the families of disabled children. People will not agree to marry their daughters to the brother of the disabled child and others will not marry the sister of the disabled child. It is due to the fear that this disability might be dominant and they might eventually have disabled children. Because deafness is considered to be a disability, it is included in the overall reaction to disability in the Gaza Strip, work is being done to reduce the severity of reacting against families of deaf children. 8 cases of deaf married to each other was accomplished last year. Families would refuse to marry two deaf people to each other. Atfaluna Society for Deaf Children has established a special unit to support the deaf young couples to get married. Three social workers conduct home visits to the families and discuss the matter with them, the success was not great, but it is increasing rapidly. In addition, the increased number of schools and centers of rehabilitation and the awareness campaigns that are taking place since 2002 are contributing to increasing the community awareness about the deafness and hearing impairment and many other disabilities.

The presence of all the societies and nongovernmental organizations that serve the deaf people is a good sign of the increased awareness and the attention towards the needs of the deaf people. A problem is usually rises when starting a program of deaf and hard of hearing habilitation and rehabilitation which is lack of resources. The number of deaf

educators, speech therapists and audiologists is very small. Actually there are only 2 audiologist, 2 deaf educators and 6 speech therapists working with the deaf in the Gaza Strip. Almost all of them are holders of non-related degrees but been trained outside for varying periods. All of the people who work as deaf educators are teachers of normal children who only received sign language training to be able to teach the deaf and hard of hearing children. Most of them don't know much about the deafness and the hearing problems and they need to be educated every once in a while to be able to continue serving the children. Speech therapists are also non-speech and hearing science degree holders; they all graduated from different fields and received some training on speech therapy and they work according to their limitations. This might give an idea about the habilitation and rehabilitation system in the Gaza Strip, however, the Islamic university has started a speech therapy 2 years diploma program 5 years ago. The graduates are speech therapist assistants and they only can work under the supervision of qualified personnel. The biggest problem is that there isn't enough speech therapist to supervise the big number of graduated assistants. The field of Audiology is still not tackled yet as there is not enough teachers and instructors to teach in this field, however, there are plans to start a degree in audiology soon in the Gaza Strip.

Another issue is rising in the Gazan community which is the children who are fit with cochlear implants and advanced digital hearing aids and assistive devices find no follow up at the established NGOs. Neither the NGOs nor the governmental institutions have the abilities or the expertise to follow up implanted children. No trained audiologists or speech therapists are available to follow up the equipment and the child needs. Most children were implanted or fitted with the hearing aids abroad, and the children who were implanted in the Gaza Strip 6 months ago are using devices that do not have any programming hard or software. In addition, is anything happens to their implant their families have to send it to the country where it was implanted or manufactured. 72 children are using cochlear implants in the Gaza Strip now; the manufacturing companies for those 72 implanted devices are 4 and no one in the Gaza Strip has received any training on either one of them. As a result, any early intervention program should be able to deal with those children and their families and provide them with all the needed services.

Following the previously mentioned information, any early intervention program should consider the role of the elderly in the families. Grandfathers and grandmothers are very important in decision making concerning the child. Young parents cannot take any decision regarding their child unless they consult the grandparents. When a family has a deaf child everybody will try to take care of the child, especially grandparents. They will start giving advices and interfere with all the habilitation steps that will eventually be taken.

The early intervention program that should be functional in the Gaza strip should take into consideration all the facts associated with the importance of the extended family at all levels of habilitation and rehabilitation. A successful program should use those facts to make family members' role in rehabilitation important and give family members who are in a close contact with the child tasks in the habilitation and rehabilitation.

The early intervention program also should consider the cultural and Islamic roles in the society and its effect on the families. People usually believe that having a disabled child is a decision by God to test their patience. So the early intervention program should respect this fact in addition to that, A woman cannot work with a man alone and a man cannot work with a woman alone. Usually, home visiting programs in the Gaza Strip take two people to do it, male and female. If the house has a woman only, the female parent advisor will enter the house alone, otherwise both male and female a devisors go together.

Starting an early intervention program in the Gaza strip would be effective but needs lots of work. Taking into consideration the facts previously mentioned. A successful program should include training, and awareness. Finding trainees for the program would not be easy; trainees should be ready to go through intensive training starting from scratch. They should be trained on audiology, speech therapy, deaf education and some psychology. They should know for sure that their job is not going to be easy dealing with families of deaf and hard of hearing children, who might have high expectation starting from the first visit. Any early intervention program needs funds to get started; this will be another issue. Raising fund for a new program in the Gaza Strip, with all the shortages in the basic needs will be a challenge, however, deaf rehabilitation NGOs might be willing to support such a program as an advantage of leadership. Finally, since there are not many deaf and hard of hearing children who are fitted with CI and digital hearing aids, and due to the lack of resources in funding the use of assistive listening devices, the options of modes of communication are not wide. Schools for the deaf depend 95% on the sign language with some use of spoken language with the moderately severe cases. Total communication is always the dominant mode; however it's not followed precisely due to the lack of expertise.

For an early intervention program to be successful in the Gaza Strip and be applicable to the situation there, the following points should be taken into consideration:

#### **Design:**

1- A comprehensive training program for at least 10 special education graduates as a start.

Special education graduates in the Gaza Strip receive general training in all habilitation and rehabilitation fields of almost all disabilities. Their training in deaf education and habilitation is not sufficient enough to be hired as early interventionists. As a result, 10 graduates will be chosen upon their school performance and then should be enrolled in a training program that gives them all the needed information about hearing and hearing loss, in addition to DHH habilitation and rehabilitation. They will also be trained on the home visiting techniques and philosophies to be able to deal with the DHH children and their parents. After receiving the appropriate training a group of 5 out of the total number will be chosen to work for the program

for the first year. The other 5 will continue attending the meetings and receive the continuous training with the other team members to be ready for the expansion of the program services.

2- A protocol to be followed by the trainees when they start their work.

It is very important to set up a working protocol for everybody in the team to follow throughout the work. Everybody in the team should be very careful with the steps taken in the habilitation or rehabilitation process. This protocol is important that everybody will be following the same steps and criteria for that all DHH and their families are going to receiving the same services with the feeling that the early intervention team is speaking with one mouth which will increase the families trust of the team and will as a result should increase community trust and support to the program. This protocol should clearly address the structure of the home visit, the activities that will be done during the home visit, the relationship with the DHH child and the caregivers, in addition to the filing and reporting. Having this protocol will make it easy for everybody to be on the same track and will make it easy to follow up the workers and evaluate them.(appendix 2)

3- At least one introductory workshop in each city for the families of DHH children to introduce the program and discuss their expectations. Because it is going to be a home visiting program, people should know what is the nature of this program prior to seeing the early interventionists in the field. In addition, families of the DHH should also express their expectation and discuss them in an open discussion. Therefore, it is very functional to hold meetings and workshops in each city in the Gaza Strip for the families of the DHH children, other deaf schools representatives and local community leaders. During those workshops, the program manager and Atfaluna public relation officer should introduce the program to the attendees, making clear what are the activities, goals and objectives, then open the discussion for the attendees to express their concerns and Those workshops will help in establishing a common expectations. understanding of the expectations and outcomes of the program and will lead to initial support for the team that is going to be working in the field. (Appendix 2)

4- A written instruction booklet including all information about hearing, hearing loss, habilitation and rehabilitation of DHH children, and hearing aids troubleshooting.

A parent manual is one of the important tools that will be distributed to the parents of DHH children. This manual should include all the needed information about hearing loss, habilitation, hearing aids troubleshooting and speech/language acquisition. Each family should have access to this manual and should be able to discuss any unclear points with the early interventionist. This manual is very curtail for the caregiver to have as a guidance of information on how to deal with their DHH child in addition to how to tackle the problems that might happen when the early interventionist is not there. (Appendix 4)

5- A website connected to the program to provide immediate information and answer questions about new data.

Internet has become a very important tool of communication and data collection. Almost every house in the Gaza Strip now has internet access at home. As a result, the early intervention program should use this important means to facilitate families' access to information. The program will have its own website that will be addressing early intervention at all levels, and will provide the families of the DHH children of a reliable data source. In addition, the website will have a forum where anyone who is looking for information in the field of DHH habilitation and rehabilitation can meet at this forum and discuss their concerns, ideas, suggestions, and learn from others' experiences.

The website and the forum will be administered and followed up by the public relation officer of Atfaluna and the manager of the early intervention program. The information that is going to be posted on the website will be reviewed and discussed both of them. The website is going to be dynamic with new information concerning DHH habilitation, rehabilitation and new technologies. The forum will be a good chance for the families of the DHH children who are not receiving early intervention services and for the DHH adults to ask questions and discuss ideas with professionals, they can post their questions and suggestions and a specialized professional will answer the question depending on the nature of the question or the idea.

6- Families should understand their role in the program and what they have to expect from it.

The family's role in the early intervention program is very important. Since the program is going to be family centered, this means that the families of the DHH children are the key factor in providing the child with effective services. The families of the DHH children are the decision makers for their children in many fields. As a result, families should understand their rule and be ready to take the responsibility for the future steps that are going to be taken with their child. Therefore, the program team members should meet with the families before starting the actual services and discuss with them their role, and their expectations. Families should be aware that the services will not be successful and will be stopped if they don't provide the early interventionist with the needed support and trust. In addition, it will be their job to follow up the instructions and continue with the needed activities at home during the weekdays. Their interaction with their child and their work at home is very important to reach the ultimate goal they set with their early interventionist.

- 7- Social and Islamic rules should be considered in the design of the program. The Gaza community is governed by very restricted by social and religious rules. Since more than 98% of the people in the Gaza Strip are Muslims, Islam is playing a very important role in all life aspects. A functional and successful early intervention program should take this fact into consideration when being implemented. Any contradictions or oppositions to those rules might lead to hostility towards the program which for sure will destroy it. (appendix 2)
- 8- Since the technology of new hearing aids and cochlear implants is not very common in the Gaza Strip, the program would not be able to provide the families with many modes of communication. The only successful mode that is taking place now is the total communication (use of signed and spoken language together).

Families of DHH children will usually be looking for oral spoken language as the mode of communication of their children, no matter what degree of hearing loss they are experiencing. It is so hard to convince them with the fact that it is hard to achieve this goal with the limitation in resources that the Gaza Strip is experiencing. As a result, it is important to make it clear for them that the use of auditory/oral techniques is going to be difficult, especially with profound hearing loss, and provide them with all the explanations and data that clarify this fact. Sign language along with auditory/oral techniques will be used will all the targeted DHH children who suffer a moderately sever to profound hearing loss. Auditory/oral only with no sign language will be used with children who have mild and unilateral hearing loss, with normal mental abilities. (appendix 2)

9- The program should be dynamic and able to change with the developments.

#### **Chapter V**

# **Data Collection and program implementation**

# Methodology:

The method of design for an early intervention program that fits that Gaza Strip and eventually other parts of the Arab world depends on collecting data about existing programs in the United States. Programs that are functional and producing good results, that is satisfactory for the parents and the child. Since the design principles of the Gaza program have been mentioned in the previous section, it was very important to look for details that will fit all the limitations and constraints that are associated with the overall situation of the Gaza Strip. As a result, a questionnaire of 23 questions was formulated to collect information about the designs of each early intervention in 7 states (Missouri, Idaho, California, New York, Wisconsin, Vermont, and Colorado). The questions were set up in a way to help tackling each item in the early intervention program of each state. (Appendix 1)

# **Sources of Data:**

A wide net of information gathering was used to collect the data that was used to formulate the early intervention program for the Gaza Strip. Attending the EDHI international conference in Chicago February, 2010, and meeting with the national American leaders in the field of early intervention has helped in collecting data from many reliable resources. In addition to attending some of the workshops that were talking about the experiences of some states and the production of new studies and results. All together helped in clearing up the view of the future early intervention program for the Gaza Strip. Meeting with Dr. White, and Dr. Yoshinaga-Itano, as leaders in the field of early detection and intervention, in addition to attending a lecture for Stredler Brown, was a great opportunity to be informed about many of the new developments in both early identification and early intervention of DHH children. In addition to being introduced to some of the EDHI programs in the USA such as Jill Ellis from California, Terry Kegan from Vermont, Christy Cronheim from Idaho, Sherry K. Kimball from Wisconsin, Marilyn Curley from New York and Betsy Brooks from Missouri. This opportunity in the Chicago EDHI increased the possibility to have access to a variety of EDHI programs in different states. Establishing a network with some EDHI programs was the goal to inspire the foundation of the Gaza EDHI program that will be implemented eventually.

In addition to networking with some of the EDHI programs in seven states, attending some home visits in Colorado, helped in increasing the understanding of the nature of the services that are provided to the DHH children and their families. It helped in giving a clear overview of the formulation of the home visit's activities and structure. In addition, it was very helpful to observe the family and child reaction to the parent advisor and to the information that are given to the child and the caregivers. Questionnaire answered by seven EDHI programs in seven different states. In addition, each program has its website and guiding informative materials. Looking deeply into the programs and the services that they provide gave me a clear idea about the design principles and rules. All programs agreed on the point of using a family centered program, where the family is the key factor in the success of the program and the type of service the program is going to provide to the child and his parents eventually. Since EDHI and ED programs are mandatory in most of the states, each state has its own way to set up the program and use whatever material to support the program. All the seven states that replied to my questionnaire use their own way of setting up the goals and plan of action to work with the DHH children and their parents.

# **EXAMPLE 3** Analysis of Programs and Design Principles:

# Table 1

Program	Missouri	Colorado	New York	California	Vermont	Idaho	Wisconsin
No. Of enrolled children	27	350	14	50	19	1916	No records
Number of served children for the last 2 years	50	Changeable, not been reported	35	100	40	2000	40
Type of	Family	Family	Family	Family centered	Family	Family centered	Family
program	centered	Centered	centered		centered		centered
No. of employees	7	100	5	28	11	120	6
Qualificatio ns required	MA in either TOD or SLP	MA in deaf education, SLP, Audiology and proper training in working with young DHH	ASHA certified master degree deaf educators or speech therapists	California teaching credentials, experience in early childhood development, SLP, sign language skills.	MA in ED. Audiology or Deaf ED. Should participate in training	Different degrees. Ref. Idaho Infant Toddler Program eManual.	T least a BA in a deafness related field.
Referral	Through	Typically	No special	From pediatric	Referrals	Referral from	A formal
system	diagnosing	from	referral	audiologists,	from	diagnosing reliable	referral
-	hospitals	audiologists,	system	regional center	Audiologi	partners across the	from a
	_	could come		workers and	st and part	state	diagnosin

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		from doctors too.		community.	C office		g institute with a final diagnosis
Enrollment Criteria	Hearing loss	Any degree of hearing loss age birth to 3.	Hearing loss of 50dB or more	Suspected or confirmed hearing loss (any degree) ages 0-5	Diagnosed or suspected hearing loss.	Developmentally delayed.	0-3 having a document ed hearing loss, children with multiple disabilitie s with suspected hearing loss will be accepted in the program
Multi- Disciplinary team		Work in coordination with the multidiscipli nary team of Intervention Colorado and Centered Board	Psychologi st, behavior specialist, nurse, educational evaluator, counselor, TOD,	Teachersofdeaf,SLP.Occupationaltherapists,consultingpediatrician,audiologists,childcarespecialistsand	Occupatio nal Therapist, physical therapist, from the part C program.	Yes	ED. audiologis t, SLP, deaf ED., psycholog ist, sign language consultant and deaf-

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			speech therapist.	social workers.			blind consultant
Home visits/week	Ι	1-4 visits/month, as decided during the IFSP meeting.	Up to 5	1-2	1	Following the IFSP plan.	Consultan t program with home visits upon the need and request from the EI program.
Ongoing training for staff	Related to EI topics	Training via workshops, statewide conferences, webinars, and one on one mentoring.	SKI*HI and creative curriculum training	Ongoing monthly staff development, monthly brown bag lunch, monthly consultation with mental health and monthly consult with neurodevelopm ental pediatrician.	Must complete the SKI*HI training. Vermont has 2 certified SKI*HI trainers.	Program eManual.	State laws, legislation s. IDEA laws, and meeting consultant s areas of need.
Training manual	No	Chip parent manual.	SKI*HI and regular	No. Have an employee	No	Special eManual Heathandwelfare idah	NO

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Mode of	Verbal, no	Signs are	Use of	Total	Use of	According to family	Use of
communicat	sign	used if the	ASL,	communication,	sign	need, yes.	sing
ion used	language	family	bilingual	signing exact	language		language
		chooses it as	philosophy	English and	of families		if needed
		a	•	voicing at the	who ask		
		communicati		same time.	for it.		
		on option.			Assigned		
					deaf		
					mentor		
					will train		
					them.		
Age of	0-3	Anytime the	Birth	Birth for home	As early	0-3	0-21 years
illegible		child is		visits, 12-16	as		old
enrollment		identified		months for	possible		
		with hearing		center based,			
		loss at the		first with parent			
		age from 0-3		and then 18			
				months in the			
				toddler class			
Program	Individuali	Family-	Skilled	Expert and	Skilled	Family centered	Team
Strengths	zed	Centered,	staff,	committed staff.	staff work	program dedicated to	diversity.
	programmi	outcome –	families	Comprehensive	in a small	providing EI services	
	ng for both	based, data	support,	services, high	state and	to children and their	
	child and	driven with a	focusing	standards and	the	families.	
	family,	rich history	on	creative	relationshi		
	center	of outcome	language	curriculum.	p that		
	based	data on the	developme		have		
	toddler	children and	nt and		evolved		

w gr in na m su gr p; cu an an su	veekly group nformatio al neetings, upport group, barent coaching ind udiology ervices.	Highly skilled providers, skilled mentors.	environme nts to support overall growth of the child.		audiologis ts, other service providers.		
Needed M developmen ts	Aore Staff	Not answered	Offering evening and weekend home visits, unlimited supplies of dvds, cds and books to leave with the families for them to keep.	Free hearing tests, better payments for teachers.	Get parents together on a regular basis. A library for each office.	Full time jobs for contracted specialists.	Solid foundatio n for regional teams in the state with expertise in EI for DHH children.
Amplificati O	Onsite vorking	Clinical audiologist	Audiologis t that is	Teachers and parents perform	Audiologi st who	Onsite audiologists who are responsible	Audiologi st

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troubleshoot	audiologist		responsible	regular testing	deals with	for amplification	responsibl
ing	responsible		for the	on the	the	follow up.	e for
C	for fixing		amplificati	amplification	problems	L L	consultati
	amplificati		ons of the	system and if	of		on and
	on		children	there is a	amplificat		solving
	problems		and the	problem it will	ion and		the
	•		support for	be referred to	solves		amplificat
			the team.	the Audiologist.	them.		ion
				-			problems.
Special	My baby	CHIP parent	SKI*HI	Creative	SKI*HI	SKI*HI	No
curriculum	and me	manual as		curriculum, talk	and Deaf		specific
	book.	well as		around the	Mentor		curriculu
		SKI*HI.		clock and			m
				AuSplan.			
Deaf adults	None	Access the	Mentoring	Teachers and	As	No	Deaf
role		deaf role	program	supporting staff.	Mentors		mentors
		model	for deaf		to teach		and staff
		program	adults to		families		members.
		administered	contact and		ASL or		
		by the	support		other		
		Colorado	hearing		signed		
		school for the	parents.		systems.		
		deaf and					
		blind. Also					
		there are deaf					
		professionals					
		employed as					
		regional					
		coordinators					
		and CHIP					
66							
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	parent facilitators.						

Comparing the surveyed programs in the previous table it is very clear that all programs are family centered, they all use continuing education to improve the skills of their employees and all of them are using a specific curriculum. Six out of the seven programs are using sign language and 5 are using total communication techniques. All of the programs have a referral system and will work with children who are either diagnosed with hearing loss or are waiting to be diagnosed. The enrollment age is from 0-3 years old, and 6 programs out of the 7 don't work with more than 50 children a year. A multidisciplinary approach is used by all the programs, including all needed disciplines to work with the DHH and their families. In most of the programs the required certificates for the working team shouldn't be less than MA in one of the deaf habilitation and rehabilitation fields.

Since the analyzed programs in the table are similar in almost all the characteristics, and all of them are successful and functional, it will be good to combine the good characteristics that will fit the situation in the Gaza Strip and put them together in the early intervention program that will be implemented in Gaza. One big issue and challenge that faces all the program is the fund. Most of those programs don't have the needed fund to implement all the activities they plan to or wish to have. This matter should be taken into consideration when starting the implementation of the Gaza program. Sufficient funds should be guaranteed by the donors and the implementing organization to insure the correct and strong start of the program. Since, the implementing organization is going to be Atfaluna, it is guaranteed that the program will

be funded through the European Union (EU) commission office in Gaza and the middle east. Atfaluna has applied for fund for an early detection and early intervention program to be implemented in the Gaza Strip, for three years. The first 2 years of the project will be devoted to the early detection of DHH newborns, and then the funds in the last year are going to be for the early intervention program to work with the detected DHH children and their families. While the early intervention program is started, application for continuity fund will be placed. All funding organizations will be willing to support the program upon the outcomes and the reports of the beneficiaries. As a result, the first year of program implementation will be very important to provide the donors and the local community with a convincing outcome that will guarantee its continuity.

# **Program Personnel:**

The employees of the program will be working under the managerial structure of the program itself, which will be administered under the administrative system of the whole organization. Employees will be recruited following the program need that was determined through a series of meeting needs assistance, in addition to the assigned budget by the donor. The following team is the team that is going to be the core of the program as the start:

# 1- Program manager

The Director of the outpatient clinics will be the program manager.

2- Social workers

Working for the ASDC as full time and will be working for the EI program part time.

3- Psychologist

Working for the ASDC as full time and will be working for the EI program part time.

4- Five early interventionists

Will be chosen out of a group of speech therapists or audiologists assistants, who have a diploma in the field of speech therapy or audiology.

5- Accountant

The accountant will be serving the project through his/her job at ASDC. It is the accountant responsibility to follow up the budget and financial needs of the project and will also be responsible for all the needed financial reports that should be presented to the donor.

6- Secretary

The secretary of ASDC will be responsible for coordinating the work of the EI team through calling the families and receiving calls and notes from families and other organizations.

7- Sign Language Instructor:

The sign language instructor is a position that is under the school structure. Since ASDC holds ongoing sign language courses, the EI team will be attending the courses upon their skills level.

# 8- Deaf Mentors

Deaf mentors are going to be selected from the teachers' assistants group at ASDC school. They will be working with the EI team and the families to give opinions and consultations on the habilitation processes.

9- Drivers

The drivers who work a full time job for ASDC will also be working for the EI program as it is considered to be one of its programs. They will be responsible to transport the teams to the locations of their home visits according to a set plan.

# **Implementation:**

The EDHI program for the Gaza Strip is going to be one of the projects of Atfaluna Society for Deaf Children. It is one of the biggest deaf organizations in the Gaza Strip. Since Atfaluna has started and early identification program of hearing loss, it is crucial to follow it by amplification and early intervention. Therefore, the program is going to start January, 2011 by the training and preparations. The actual home visiting activities will start 2 months after the initial start of the program.

The implementation of the early intervention program at the beginning will depend on the external funds to be functional and self sufficient as a standing program that serves all DHH children and their families. As a result, Atfaluna has already received the funds for the EDHI program for one year. The program is going to be run under the administrative structure of the whole organization. It will be run and supported by the personnel of Atfaluna, however, it will have its own crew. The working team is going to be technically responsible from the program manager. The team itself will be standing by itself as a separate program, financially and technically, however, it is going to run under the hierarchal structure of Atfaluna. The program will serve 40 children as a beginning; each early interventionist will work with 8 children weekly, visiting 4 children a day twice a week for one hour.

# **Evaluation:**

The early intervention program as previously mentioned is going to be implemented as a pilot project that is going to be funded by the EU commission in the Gaza Strip. The funding agency will have its own evaluation requirements that will be mentioned in the contract. However, the internal and external evaluations of the program will be done by the program employees in addition to Atfaluna administrative staff. The team is going to meet every week to evaluate the weekly activities and set up the plans for the next week. Meeting discussions and memo will be kept to be summarized in a monthly report. A monthly report should include all the activities and accomplishments, in addition to the challenges and problems the team has faced during the month. The report should be delivered to the general director of the organization to be able to follow up the program, in addition to a copy of the report that should be sent to the director of the project which will turn it to the donor. Every three months there should be an evaluation meeting that will be held at Atfaluna. The evaluators will be from the families of the DHH children, directors of other deaf organizations and community leaders. A representative of the donor agency will be invited to attend the evaluation meeting. The evaluation committee will review the reports, listen to the families and access some of the files. Recommendations will be written and sent to the general director of Atfaluna who will send it to the manager of the early intervention program for action. At the end of the program, international and national expert, in addition to the donor agency representatives will perform a professional evaluation on all program funds will depend on the outcomes of this evaluation.

### **Recommendations:**

An early intervention program for the Gaza Strip is very important for the fact that the number of newborn with hearing loss is very high. As a result this will be a good chance to provide needed services to this group of people and their families, which at the end will hopefully result in a positive impact on the community. As a result the following recommendations will make it possible to start a functional program that will eventually serve all the DHH children:

• Convincing the local community and families of DHH of the benefits of the program and gain their support.

- Convincing the donors of the importance of the program and the huge outcomes that will result from its implementation.
- Follow the infrastructure protocols and materials for the program to succeed and achieve its goals.
- Make the deaf community and deaf leaders' participation in the program as active as possible.
- The program should be implemented under the administrative structure of a working organization that is trustable by the community and the families of the DHH children.

# **Conclusions:**

As a result of all the previous work of literature review and programs analysis, it was concluded that it is important to establish an early intervention program for the Gaza Strip to serve the large number of the DHH children. Since early identification of hearing loss is being functional in Gaza, the number of young children who are less than 3 years old who are identified with hearing loss is dramatically increasing. Those children and their families will be the target for the early intervention program that will be associated with this work. The early intervention program for the Gaza Strip should take some aspects into consideration that includes family structure, Islamic rules and social traditions. A successful program should respect those aspects and work according to the structure of the Gazan community. Training and manuals that are developed will be used to insure the continuity of the program and that the services that are provided to the DHH

children and their families are up to date. The success and continuity of the program will very much depend on the families and community support as well as on the team work of the program team.

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# Appendices

- 1- Questionnaires.
- 2- Infrastructure of the early intervention program for the Gaza Strip.
   3- Early interventionist training manual.

# Appendix 1:

# **Questionnaire of the early intervention programs:**

- **1.** Name of the Programs:
- **2.** Name of the responding person:
- **3.** Position of the responding person:
- **4.** Date of Completion:
- **5.** The state/s where the program is functional:
- **6.** Number of children the program is serving now:
- **7.** Number of children the program has served in the last 2 years. (Who is still in service and who is out?)
- **8.** Is the program family centered? Yes No
- **9.** How many workers:
- **10.** What are the qualifications for a person to work for your EI?
- **11.** Do you have a special referral system? How does it work?
- **12.** What is the enrollment Criteria for the children in your program?
- **13.** Do you have a multi disciplinary team? Who serves in it?
- **14.** How many home visits a week do you give the child who is in service?
- **15.** What kind of training do you give your workers?
- **16.** Do you have a special training manual for the workers? Can I get a copy of it?
- **17.** Do you use sign language? How does it work in you program?
- **18.** At what age the child is eligible for the program?
- **19.** What do you think the strengths of your program are?

- **20.** If you could, and have enough resources, what are the changes that you would like to make to your program?
- **21.** What are the responsibilities of the person who deals with the amplification problems?
- **22.** Do you use any curriculums such as SKI-HI?
- **23.** How do you involve deaf adults in your program?

# **Appendix 2:**

# Infrastructure of the Early Intervention Program for the Gaza Strip:

# **Introduction:**

This program is going to be used in the Gaza Strip (Palestinian territory) with the deaf and hard of hearing children (DHH) and their families. The program will be implemented through a funded project by the European Union Commission in the Palestinian Territories and the Middle East for one year. The funds will be used to establish the infrastructure for an ongoing functional program that serves the DHH children all over the Gaza Strip. It will be administered and followed up by Atfaluna Society for Deaf Children (ASDC), which is implementing an early detection program that is targeting the newborns at the Primary health care units. The Early Intervention program will be serving the newborns that are detected with a hearing impairment. As a result, both programs will be working in full cooperation and will be coordinated. Children with all degrees of hearing loss once it is detected and confirmed will be enrolled in the program. Family support and use of educational techniques will be important for the newly detected children to set up a habilitation plan. Children with mild to moderate hearing losses and children with unilateral hearing losses will be included in the program for orientation and support. Once the children are fitted with the suitable amplification systems, children with middle to moderate and unilateral hearing losses will be discharged from the program and will be referred to a speech/language therapy program. Children with moderately sever to profound hearing losses will

continue to receive the services even after they receive their amplification. The use of any mode of communication with those children will depend on the degree of benefit they will receive from their hearing aids and the family support and cooperation with the early intervention team.

It is important to mention the difference between DHH habilitation and rehabilitation, as habilitation or rehabilitation is the process of accessing the residual hearing of a DHH person through the use of assistive devices and/or auditory training techniques. The term "habilitation" is usually used with children who are prelingually deafened or DHH, and the term "rehabilitation" is used with any DHH of hearing person who lost their hearing after acquiring speech and language. Hearing habilitation seeks to help the DHH child develops skills that are not present such as the ability to use the residual hearing and oral language or a signed language that make it possible to communicate. . In addition, the child who is born with a hearing loss should be trained on using all means to access sound for the reason that hearing parents often want their DHH children to understand and produce speech sufficiently well to communicate in the hearing world. They choose spoken Arabic as the child's intended primary language, since it matches their own. Other parents envision sound as an adjunct to sign language and/or speech reading; their chosen language may be sign or spoken Arabic. Still others, particularly those whose children have profound hearing loss, are more concerned about the child's safety. They want the child to be able to hear warning sirens, trucks backing up, car horns, and fire alarms. Speech is not as important to these parents, so they usually choose sign language as the child's main form of communication. With the new techniques in hand such as cochlear implants and digital hearing aids, profound hearing loss is being partially solved and the young children who receive suitable amplification on time will be able to use their hearing to develop spoken language. However, those new techniques are still not available and fully accessible in the Gaza Strip. As a result, depending on sing language will stay important for the time being.

For those who became DHH after learning spoken language, the primary goal of rehabilitation is to restore a lost function. Individuals who experience hearing loss in adolescence or older usually do not have great difficulty with speech production, since they are familiar with the movements necessary and receive feedback from the muscles to determine accuracy. Younger children, whose speech patterns are not as defined, may have more trouble producing intelligible speech (depending on the degree of hearing loss). Also, they are still learning language, so they need extra attention in that area of development. For both groups, speech perception is essential.

The program will be funded through Atfaluna Society for Deaf Children (ASDC). It is a nongovernmental organization that works with DHH children and their families. Atfaluna has launched a newborn early identification program in the Gaza Strip targeting the primary health care units of the United Nations for Relief and Work Agency (UNRWA). Following this program, the early intervention program will start working with the children who are indentified with hearing loss. The program is going to be funded by the same funding agency (European Union office in the Middle East, EU).

# **Program Development:**

The program should take into consideration all the community and life aspects in the Gaza Strip that will be either limiting or supporting the staff and the deaf school to be able to implement it. For example, it is important that the EI program should understand and carefully deal with the family structure and include the elderly decision makers in all the decisions that will be made along the habilitation process. In addition, the program should respect the social and religious traditions and rules when starting the actual home visiting. Women EI should be properly dressed and covered and should respect the house they visit, in addition, women cannot visit a house with the only the father there alone, there should be a woman and a man in the team. The previous examples give an idea about some of the community and life aspects EI team should take into consideration, if not the community will reject the program and will refuse to deal with it and will deprive the DHH from the service which will limit the success of the program and lead to a complete failure. The following characteristics should be taken into considerations:

# 1- Community.

2- Families

# **Community:**

The Community of the Gaza Strip is a closed restricted Muslim community. Almost 98% of the people in the Gaza Strip are Sunni Muslims who follow the Islamic instructions

and rules. In addition to the Islamic rules there are social traditions that influenced the families and the social relationships. Any family that has a disabled child believes that this child is a gift from God to test their patience and acceptance of God's will. As a result, it is very important for the staff that will be working for the EI program to understand this concept and respect those beliefs. The program should gain the community support and be trusted by the community members so it will succeed and be beneficial. If the program does not gain the community trust it will be impossible for it to be functional. As a result the program should work on convincing the community for support before it starts. It will be better to announce the program to the community before starting the actual work, because it would be awkward to see the staff knocking the doors and getting in the houses without being announced and known by the local community. The following will support the program integration into community:

# 1- Atfaluna reputation and respect in the community:

Since the program is going to be working under the supervision and support of Atfaluna Society for Deaf Children, which is a well known respectable organization; this will be the first step towards gaining the community trust and support.

### **3- Workshops:**

In addition, there should be several workshops to announce the project and to discuss the community needs. Workshops should be held in each area of the Gaza Strip separately. During those workshops, a supporting committee should be either elected or chosen by

the attendance to work on supporting the project in the community and follow it up. This committee is going to be very important in order to provide solutions to all the challenges the staff might face with the local community such as families refusing to cooperate with the team due to certain religious or social beliefs and some neighborhood leaders who might refuse to allow the team to visit houses.

### 4- Community representatives:

Through Atfaluna, the program should call for a meeting of community representatives such as legislative council members, Mosques imams and representatives of other NGO that work with the DHH children. In this meeting, the program manager and Atfaluna administrative staff will discuss the program with this group of important people to convince them and gain their support. Gaining the support of this group of people will lead to gaining the support of most of their followers and workers which means almost all people who are concerned in developing the community and supporting disabled people.

# 5- Media:

Finally, media should be used too to announce the program and its benefits. Local radio stations and televisions would be a good medium to reach every house and talk openly about the program, why it's needed and what are the expected outcomes.

# **Families:**

The program should be family centered. It is very important to deal with the family issue in a way that pays close and careful attention to the extended family. The extended family is very important in the social structure of the Gaza Strip. It is usually about dealing with all the people at the house considering everybody responsible for the needs of the child. Usually the family of the DHH child lives within a bigger family structure. Older people in the family should be consulted about the decisions that will be made. When having a DHH child in the family, not only the parents will be in charge of making the decisions, the grandparents, uncles and aunts will also share in decision making and sometimes they might refuse some decisions that have been made by the child's parents. As a result, the program should be designed to make a good use of the extended family's role in the habilitation process.

Prior to starting the actual home visiting program, the staff members who will be assigned to work with each families will perform an evaluation of the family structure and identify the decision maker and the way decisions are made regarding the DHH child. The early interventionists have to be aware of the family structure and ask to include the older people in the decisions that will be made for the child (more explanations in pages 12-15). Ignoring other people who might be important in decision making might lead to an ineffective relationship with the family and less or no benefit to the child. Understanding the family structure and dealing with each family as unique will help to provide the child with the best service, in addition to enlarging the number of caregivers who will be willing to learn the techniques to help the child and his parents.

# **Structure:**

# Administrative:

The program will follow the administrative structure of ASDC. ASDC has a general manager, and a program manager for each of the programs that are functioning in the society. The EI program will follow the same administrative criteria of working hours, salary chart, job requirements and financial issues; and will be hierarchically set under the administrative structure of Atfaluna. Financially, the EI program will get its budget through the EU fund. The financial manager of Atfaluna will be responsible for all the financial aspects of the program and will be in charge of the payments and the costs of each single item.

# **Employees:**

The employees of the program will be working under the managerial structure of the program itself, which will be administered under the administrative system of the whole organization. Employees will be recruited following the program need that was determined through a series of meeting needs assistance, in addition to the assigned budget by the donor. As the program will be a pilot project for one year, the team will be:

### 1- Program manager

The Director of the outpatient clinics will be the program manager.

10-Social workers

Working for the ASDC as full time and will be working for the EI program part time.

11-Psychologist

Working for the ASDC as full time and will be working for the EI program part time.

### 12-Five early interventionists

They Will be chosen out of a group of speech therapists or audiologists assistants, who have a diploma in the field of speech therapy or audiology.

13-Accountant

The accountant will be serving the project through his/her job at ASDC. It is the accountant responsibility to follow up the budget and financial needs of the project and will also be responsible for all the needed financial reports that should be presented to the donor.

### 14-Secretary

The secretary of ASDC will be responsible for coordinating the work of the EI team through calling the families and receiving calls and notes from families and other organizations.

15-Sign Language Instructor:

The sign language instructor is a position that is under the school structure. Since ASDC holds ongoing sign language courses, the EI team will be attending the courses depending upon their skills level.

**16-Deaf Mentors** 

Deaf mentors are going to be selected from the teachers' assistants group at ASDC School. They will be working with the EI team and the families to give opinions and consultations on the habilitation processes.

# 17-Drivers

The drivers who work a full time job for ASDC will also be working for the EI program as it is considered to be one of its programs. They will be responsible to transport the teams to the locations of their home visits according to a set plan.

The manager, social worker and the psychologist will be working part time and the other 5 early interventionists will work full time. The manager, will work 2 hours daily for the program but the social workers and psychologists will be working as full time for the ASDC and will be called to support the team when needed. Their working hours will be determined by the program manager and this will be decided during the weekly meetings with the team. They will be paid according to their working hours. The working hours of the program will be the same working hours as the whole NGO, from 8 am to 3 pm.

Logistic and financial aspects for the working team will be taken care of by the financial manager and accountants of Atfaluna, each early interventionist will be contracted for one year and the contract will be renewed following their performance and achievements. Early interventionists should be in a direct contact with their manager to meet their needs and try to provide them of all the items that are needed for their work. They will be using special internal forms to order their expenditures and logistics such as papers, pens, files, toys, workbooks, colors, educational toys, and coloring books, and then hand it to their manager who will hand them to the purchasing department.

Areas of knowledge and competencies:

The employees of the EI program should be knowledgeable in the field of deaf habilitation and rehabilitation. Everyone in the team should be trained on the techniques of early intervention and DHH children habilitation and family orientation. It is very important for the early interventionists to be trained on the different ways of dealing with families and their children and on the possible threats to the success of the habilitation plan and what are the techniques required to overcome those threats. Family role is the most important role in the process of rehabilitation, so every early interventionist should know how to tackle this issue and deal with it for the benefit and success of the program the team members and areas of knowledge and competencies are:

- Program Manager
- Psychologist
- Social worker
- Early interventionists

Every one of the team members should be knowledgeable and trained on the following items, however, the manager, psychologist and social worker will have enough experience at the basic information regarding sign language, anatomy and physiology, DHH habilitation and rehabilitation and family orientation. Therefore, they shouldn't attend the training in those fields but should attend the training on other fields. The early interventionists however, still need to receive comprehensive training in all following fields.

- 1- Hearing loss anatomy and physiology.
- 2- Palestinian sign language.
- 3- Deaf habilitation and rehabilitation techniques and processes.
  - a. Training in auditory perception. This includes activities to increase
     awareness of sound, identify sounds, tell the difference between sounds
     (sound discrimination), and attach meaning to sounds. Ultimately, this
     training increases the child's ability to distinguish one word from another
     using any remaining hearing. Auditory perception also includes developing

skills in hearing with hearing aids and assistive listening devices and how to handle easy and difficult listening situations.

- b. Using visual cues. This goes beyond distinguishing sounds and words on the lips. It involves using all kinds of visual cues that give meaning to a message such as the speaker's facial expression, body language, and the context and environment in which the communication is taking place.
- c. Use of sign language: This will help the caregivers and the child to establish a mean of communication as early as possible, especially prior to receiving the amplification.
- d. Improving speech. This involves skill development in production of speech sounds (by themselves, in words, and in conversation), voice quality, speaking rate, breath control, loudness, and speech rhythms.
- e. Developing language. This involves developing language understanding (reception) and language usage (expression) according to developmental expectations. It is a complex process involving concepts, vocabulary, word knowledge, use in different social situations, narrative skills, expression through writing, understanding rules of grammar, and so on.
- f. Managing communication. This involves the child's understanding the hearing loss, developing assertiveness skills to use in different listening situations, handling communication breakdowns, and modifying situations to make communication easier.

- g. Managing hearing aids and assistive listening devices. Because children are fitted with hearing aids at young ages, early care and adjustment is done by family members and/or caregivers. It is important for children to participate in hearing aid care and management as much as possible. As they grow and develop, the goal is for their own adjustment, cleaning, and troubleshooting of the hearing aid and, ultimately, taking over responsibility for making appointments with service providers.
- 4- Cooperation partnership with families.
- 5- Assessment of the child and family need.
- 6- Psychology of the family of the DHH child.
- 7- Reporting and evaluation.
- 8- Hearing aids troubleshooting.
- 9- Modes of communication.

Each early interventionist will receive a training course of 2 months. The training course will be held at Atfaluna training center and will be given by an audiologist, speech therapist, psychologist and social worker. Each trainee will receive 100 training hours. The initial group of trainees will be 7 to 10 people who have a 2 year degree of audiologist assistant or speech/language therapist assistant. Out of the trainees group and depending on their performance in the training course 5 people will be chosen to start working for the EI program as early interventionists. The 5 early interventionists will

start working for the program immediately after the training course, following a list of families that will be prepared by the Audiology outpatient clinic.

Each early interventionist will meet and work with specific families. Each early interventionist will work with 10 families as a beginning, in terms of home visits, meetings and sign language training courses. The first meeting that will be held will be to introduce the families to the early interventionist who is going to be working with their child and for the early interventionist to know the family, meet the child and get the chance to discuss the family structure and the logistics, timing and decision making. It is important to talk with the family about their expectations and needs and find a common understanding towards a better service to the child. This meeting is very important o break the ice and establish an initial trust between the family and the early interventionist, for that when he/she starts the home visits, the families will know who and what to expect. In this meeting families will meet with the audiologist, the speech therapist, the social worker and the psychologist. They will be introduced to the whole team that is going to be working with them and will also have the chance to meet with other families and listen to their experiences.

# Home visits:

This program is going to be a good chance to train some of the school teachers on early intervention techniques in addition to increasing the number of the early interventionists for future expansion of the program. It will also be a good peer mentoring experience to increase the programs efficiency and effectiveness. This will provide each early interventionist with a mentor who will point out their weaknesses and strengths and will discuss improvements of the plans and the actions (more explanations in page20).

After the training and the meeting with the families, each early interventionist will set up his/her own working schedule in cooperation with the program manager. The program manager will be responsible for providing the team with its needs and logistics. The schedule will be full with a full load work as the team members will be full time employed. Each early interventionist will work with 5 children a day starting at 9 am to 2:30 pm with half an hour lunch break in the field. The work day will start at 8 am. The team will leave the center and go to the field at 8:30 am. This gives them a chance to meet in the morning, prepare their files and get ready for their work. The early interventionist will visit the same child twice a week. They will be two groups of 5 families, Sunday and Tuesday is one group and Monday and Wednesday is the other group. Thursday will be in the office day, for lectures, discussions, paper work and other preparations for the next week.

The early interventionist team will leave the center in the same care and will work in the same area every day. Starting at the northern area of the Gaza Strip (Beit Hanoun, Beit Lahia, Jabalia and Sheikh Radwan), then Gaza City (Beach Camp, Shegaiah, Nasser, Zaytoon, Tal al Hawa and Remal), then the middle camps (Nussirat, Burij, Maghazy and Deir al Balah). The south will be covered later, following the success of the program and the available fund.

Covering those areas will be difficult, so there will be a committee to decide which areas should be covered first. Since the program will only work with 50 children at the beginning, the areas where the work will be conducted should be close to each other so that the whole team works in the same area which will make it easy for the car to be around them and pick them up and move them to the next house. Houses where is only the mother in the house should be visited by a female early interventionist and houses where is only the father in the house should be visited with a male early interventionist. It is for the team members and the program manager to decide which houses will need to be visited by both male and female early interventionists. It is usually needed when there is only a male caregiver with the child in the house. In this situation, a female early interventionist cannot enter the house alone; a male partner should accompany her. When there is only a female caregiver with the child in the house, a male early interventionist cannot enter the house alone, he should be a companied with a female partner.

The first home visit will be devoted for collecting data and completing the file and discussing with the family all the organizational issues for the future work. Files should be completed at the first home visit with the following data:

1- Name:

- 2- DPOB and Age
- 3- Address
- 4- Phone/Cell number
- 5- Type and degree of hearing loss
- 6- Referring source/contact person
- 7- Mode of communication.
- 8- Previous services
- 9- Family type/ extended or core
- 10-Citizenship status
- 11-Family socioeconomic status/ rated from 1 to 5, as one is poor and 5 is rich.

This information is supposed to be collected in the initial intake session when the early interventionist meets with the family. Data could be completed during the first home visit. The file should be completed after the first home visit with all the listed information. Files will be reviewed by the program manager, home visits will be stopped if the child's file is not completed. It is the early interventionists responsibility to fill the information and complete the file.

Each home visit will last one hour, and before going to the house of the DHH child, the early interventionist should confirm it with the family. Families in the Gaza Strip have consist of an average of 5 children and they usually live in a big house with the uncles and the grandparents. Sometimes, there are things going on the house that the parents of the DHH child can help it and wouldn't be able to have the early
interventionist visit them. Setting up the home visits schedule should be done in a full cooperation and coordination with the family. Families should also be consulted with any changes to the schedule.

Each home visit will be set in a particular way as a protocol each team member will follow. First 10 minutes are to talk with the care giver about the time between the home visits, what happened, what are the problems and challenges they faced with their child and if they have any questions or comments. 10 minutes of reviewing the last session, and 30 minutes working on two tasks. The last 10 minutes will be to wrap up the session and answer any questions the caregiver has.

#### **Family Sign Language Training:**

ASDC holds sign language courses for families of DHH immediately after the identification of the hearing loss. Parents of children with moderately sever to profound hearing loss usually sign up for the sign language training course. Since this is an education program that has been going on for almost all parents of DHH children, caregivers of the DHH child will be given a sign language training course prior to the start of the home visits. They will be given a basic course at Atfaluna, by sign language experts and deaf leaders. The sign language course should make them able to use basic signs and know at least the sign for each simple work they will be using with their child. This training course will also be funded through the EU funds and will last one month.

Following, the program team will have to attend the sign language courses that are conducted at ASDC for the staff. Those courses are categorized and leveled. Each team member will have to go through the evaluation and placed in his/her level. This ongoing training is required for all ASDC staff and will be a requirement for the early intervention team. With this intensive comprehensive training, all team members will be expected to be able to communicate using sign language easily.

#### **Deaf Mentors and assistance:**

Atfaluna Society for Deaf Children (ASDC) is a leading organization in the field of deaf habilitation and rehabilitation. ASDC has the biggest deaf community in the Gaza Strip who is working either at the handicrafts shops or as teacher assistances. The deaf people at ASDC act as an independent community with its own leaders and rules. They usually have good relationships with their hearing coworkers and act as sign language teachers. It is the deaf community goal to teach their hearing coworkers sign language and help them communicate. It will be one of the program goals to use the assistance of the deaf community at ASDC to help train the early interventionists and EI program team members, in addition to the caregivers of the DHH children on the proper use of sign language and introduce them to the deaf community. The assistance of the deaf people will be crucial to help the families of the DHH decide on the use of sign language and that their child will not be stigmatized because of using sign language. Deaf role models are very important for the program to succeed and will be helping the early interventionists a lot in their communication with the families. In addition, deaf adults could be working as mentors for the early interventionists and help them improve their techniques and performance.

#### Mode of Communication:

It is important for the each early interventionist to be knowledgeable about the total communication which is the use of any and all communication methods necessary to facilitate language acquisition. This system, which typically uses sign language, may include: speech, finger spelling, manual signs, gestures, speech reading, cued speech and augmentation of residual hearing. Basically, this mode of communication may utilize any combination of the communication options depending upon the child and his family. Some children might not be able to use speech reading due to vision problems, as a result, each child is special and could use some of the means but not all of them. In addition, they should be able to use all techniques associated with this mode of communication.

Using sign language should be in a full cooperation with the family and caregivers and should depend on the child's hearing status and use of amplification. In the Gaza strip the use of sign language is very important since the advanced technology of the digital hearing aids, cochlear implants and assistive listening devices such as the FM systems are not available and so difficult to be afforded by families. In addition, donors will rarely fund such expensive devices as they will always ask for their money to be used with as much children as possible. As a result, the only way for amplification is the use of analog hearing aids that are not very functional in providing the children who are suffering a severe to profound hearing loss with clear speech signals. Therefore, the use of sign language is very important and is the only way in the mean time to provide the children and their families with a suitable functional mode of communication.

The limitation of the options of modes of communication should be put very clear for the families of the DHH children and should be discussed with them at all levels. In light of the current situation of the Gaza Strip and the limitation of technical options, families should understand that there are not many options to choose from, and sign language should be used with their children no matter what they read and what they think of the new technology. Families of DHH children in the Gaza Strip want their children to be able to communicate using speech and will usually refuse the use of sign language with their children. The use of sign language and hearing aids are thought to be a stigma. Families will try anything for their children not to use sign language and will refuse any attempts to convince them. This will be the most important step in the whole program, convincing the families of the DHH children to use sign language with their children and for them to learn the sign language to be able to communicate with them. It is going to be a multidisciplinary goal to convince the parents with the use of sign language and there should be a representation of successful deaf mentors and role models. Working with the families should depend on their readiness to cooperate with the EI team and the early interventionist who is going to be working with them. Children with mild to moderate and unilateral hearing losses will be enrolled in the program for one month, 8 sessions to give the needed support to the family and the child and then will be

discharged for the early intervention program and referred to the speech/language therapy program. Children with moderately severe to profound hearing loss will remain in the early intervention program tell they meet the preset goals.

#### Team meeting and ongoing training:

Team meeting is a very important aspect in the EI program. The team will be meeting every Thursday, first with each other, then with the manager, the speech therapist, the social worker and the psychologist. In this meeting everyone should report their achievements and discuss the problems they encountered during the implementation Brainstorming and discussions will take place to try to improve of the plans. performance and find solutions for problems. This meeting will last for two hours, with a clear agenda and time table. As during the week, all team members should list their needs and the problems they need to discuss and hand it over to the program manager who is going to be responsible to set up the priorities and set up the meeting agenda and time table. It is possible to present some cases, discuss some family child issues and mention some needed training options during this meeting. After the meeting, training will be conducted on different fields. The training will usually cover a subject of need that will be pointed out by the team members. After the training, there will be a case presentation, every week one of the early intervention team will present a case for study and discussion. This case presentation will help everybody in the team to understand what problems they might face from a large assortment and what are the possible solutions and expected results.

The ongoing training is very important for the team members to stay updated with the developments in the field of early intervention of DHH children. Since this training will be covering subjects of interest that are chosen by the EI team, it will be helping them improving their performance. The trainers will be chosen accordingly by the manager and ASDC administration. Those trainers might be contracted from outside the society and could be specialists in many fields such as Ear Nose and Throat specialist, Pediatrician, Neurologist, occupational therapist, physical therapist. The trainer will be chosen depending on the subject of interest of the EI team. Other ASDC workers might be invited to attend the lectures in addition to some of the families who are interested to know about the subject that is going to be covered. A special item in the project budget is called ongoing training. The item will cover the training costs including the salaries of the trainers in addition to the needed expenditures.

### **Mentoring:**

Mentoring is a new strategy that is going to be used for the first time in any DHH educational program. The early intervention program that is going to start in 2011 is going to be a good opportunity to try to use the deaf mentoring technique to serve the DHH children, their families and the early interventionist. As a pilot project, 5 teacher assistances that are deaf will be assigned to work as mentors with the early interventionists. Their role will be to provide the early interventionist with the needed support in sign language, educational techniques and psychological and mental support that is needed for the child and the family. The deaf mentors will be also discussing the challenges and shortages of the abilities of the early interventionist after the home visit with the early interventionist him/herself. Since this is not going to be a mandatory part of the early intervention program, the deaf personnel will not go with the teams in all their home visits. They will be assigned to accompany the team members when is decided in the weekly meeting every Thursday. The success of this trial will make it possible to apply for funds to start a full deaf mentoring program that works with all ASDC programs.

#### **Reporting and data filing:**

Each early interventionist will be responsible for the files of his cases. It is important to keep the data filed and easy to access at anytime. ASDC will provide the EI team with all needed materials for filing. In addition, weekly progress reports and follow up papers should be filled by each early interventionist to keep the file updated. At the end of each home visit the early interventionist is responsible to fill out the progress report and the actions that been taken during the home visit in addition to the actions and goals for the future. At the office, the reports and forms should be fully reviewed and filled and properly filed. Reporting is very important to follow up the progress and the periodic evaluations.

Reports should be comprehensive including all the information about the home visits goals and plan of actions. Each early interventionist will have all the forms needed to fill out during and after the home visit. It is the responsibility of the program manager

to follow up the reporting and filing of data and that all the files are kept updated. The program manager should hold meetings with the early interventionists to discuss their reports and the progress of their cases, in addition to discussing the challenges and obstacles they might be facing. Meeting outcome should also be filed and minutes should be electronically mailed to everyone.

The program manager is responsible to provide the ASDC administration with a monthly progress report with all the details about the program progress, problems and solutions. Manager's report will be discussed in a meeting with ASDC administration and general manager.

#### **Financial aspects:**

Since the EI program is going to be fully funded by the EU project, the salaries and transportation and office expenditures will be covered by the project. Families should contribute to the cost of the expenditures and forms that are going to be used during the home visits. They have to contribute with a relatively small amount of money, just to feel that the service is important and that it is not a cheap service because it is for free. Families' contribution with a small amount of money could increase their attention and care and will take the service seriously. The amount of each family contribution will be decided by the social worker. ASDC has a chart that the social workers use to evaluate the family socio-economical status, following this chart the families will be expected to contribute to the program financially. The payment should not exceed 100 NIS (25\$) and not less than 20 NIS (5\$) a month.

The same reward scale that is used at Atfaluna for the employees will be used with the early interventionists. They will be rewarded upon their performance and achievements. Evaluations and surveys will be done to determine the performance of each early interventionist. Families of the DHH children will be surveyed and the manager of the program will perform an evaluation on the workers performance. In addition, the manager will conduct field visits to evaluate the early interventionists work on place and see the reaction of the families on the work that's done with their child. The team member who will meet the goals that are set for each case and gain the best reports by the manager and the families will be rewarded financially following the scale of reward at ASDC. Those rewards are considered to be a very good reinforcement for the workers to work harder and achieve more.

#### **Referrals and coordination:**

The EI program office is going to be located at ASDC center and school for the deaf. In the ASDC center there are all the services that are needed for the DHH and their families. It is the EI team responsibility to hook the family of the DHH child with the different services available at the center, such as the audiology clinic, the speech therapy clinic, the occupational therapist, and the physical therapist. A special referral form will be used to refer the family to the previously mentioned services. A correspondence

system will also be used to follow up the services that are delivered to the child and the family. The Audiology and the speech therapy clinics are located at ASDC and they provide services to all referred patients from many sources. They will deal with the referred patients from the EI program like any other outpatient. On the other hand, other disciplines who don't work for ASDC will be supporting the program through their NGOs in a cooperation and coordination with the EI and ASDC. Children and their families will be referred to those disciplines following the referral system that is used for similar situations for the DHH school children at ASDC.

Since the psychologist and the social worker are going to be working as part time for the program, they will be following up the needs of the families with the early interventionist and with the program manager. Both of them will be ready to provide the needed support to the early interventionist at the home setting or at the office. The social worker will be providing support in terms of meeting the DHH child and family needs, like finding funding resources for the amplification system, hearing aids batteries, other family needs, especially if the family is large and poor. The social worker duties will be completed under required assistance for the early interventionist. The psychologist on the other hand will be called to visit some families for mental support and consultation. It is important to have both the psychologist and social worker in the team to be consultants and supportive when needed. The involvement of both the psychologist and the social worker is a team made decision that will be taken after discussing the family need and the options that are available such as providing the early interventionist with the needed tools and information to help solve the raising issue or a home visit is required by either the psychologist or the social worker. Families can usually ask for help and consultation through their assigned early interventionist and could choose the place of service. All services provided to the family should be documented and filed.

#### **Employment requirements:**

## **Program Manager:**

- 1- MA degree in Audiology, speech therapy or deaf education.
- 2- 5 years experience in working in the field of deaf habilitation or rehabilitation.
- 3- 3 years experience in working with DHH families.
- 4- 2 years experience in working in the community and dealing with social issues.
- 5- Good English writing, reading and speaking abilities.
- 6- 3 years experience in human resource management.
- 7- Excellent reporting and filing abilities.
- 8- Excellent ability to use the computer.
- 9- Excellent sign language abilities.

## Social Worker:

- 1- MA or equivalent degree in sociology.
- 2- 3 years experience of working with deaf and hard of hearing people.

- 3- Good reading, writing and speaking English.
- 4- Excellent abilities of using computer.
- 5- Experience in reporting and filing.
- 6- 2 years experience in field work.
- 7- Excellent sign language abilities.

## **Psychologist:**

- 1- MA or equivalent degree in psychology.
- 2- 5 years experience in working with DHH and their families.
- 3- Excellent sign language abilities.
- 4- Excellent computer abilities.
- 5- Experience in reporting and filing.
- 6- 2 years experience in field work.
- 7- Good reading, writing and speaking English.

## **Early Interventionist:**

- 1- 2 Years or higher of education in speech therapy or deaf education.
- 2- Excellent sign language abilities.
- 3- 1 year experience in working with DHH.
- 4- Flexible and able to work under pressure.
- 5- Good reading, writing and speaking English.
- 6- Excellent reporting and filing abilities.

7- Able to use the computer.

The previously mentioned posts are the main posts for the program to be functional. Other posts and positions that will be associated with the program are already existing and working for ASDC. Accountant, driver and secretary are going to be serving the project through their positions.

#### **Appendix 3:**

## **Training manual outline**

The training of the Early Interventionists will be comprehensive and condensed. It will range from basic information to detailed information.

## 1- The impact of hearing loss on the newborn population.

#### a. Anatomy and physiology of the hearing system.

- i. Understanding parts & functions of each part of the hearing system
- ii. Understanding impact of hearing loss on the anatomy and physiology of the hearing system
- iii. Knowing the difference between treatable and untreatable dysfunctions
- iv. Being able to explain it to the families in easy terms

#### b. Communication and language disorders.

- i. Understand the relationship between speech/language disorders and hearing loss.
- ii. Understand the communication disorders associated with hearing loss in the first year of life.
- iii. Understand the language delays and/or disorders that are associated with hearing loss.

- iv. Knowing the different techniques of treatment of speech production and articulation problems.
- v. Knowing the techniques of language treatment.

## c. Anatomy and physiology of the speech production system.

- i. Understanding parts functions and dysfunctions of each part of the speech production system.
- ii. Being able to explain it to the families in easy terms
- iii. Being able to understand the difference between treatable and untreatable dysfunctions.
- iv. Speech therapy for DHH (Listening to speech production)

# 2- Skills of early interventionist.

# a. Palestinian Sign Language (PSL).

- i. The ability to use the PSL
  - e- Introductory course
  - f- Intermediate course
  - g- Advanced course
- ii. Teaching PSL to the DHH children
- iii. Teaching PSL to the families.

# b. Deaf habilitation and rehabilitation techniques and processes.

c. Managing hearing aids and assistive listening devices

- i- Troubleshooting hearing aids and assistive listening devices
- d- Training in auditory auditory training and auditory learning.
- e- Improving speech
- f- Managing communication
- g- Developing language
- h- Using visual cues.
- i- Use of sign language.

## j- Creating a partnership with families.

- i. Psychosocial challenges
- ii. Psychosocial support
- iii. Family-centered techniques
- iv. Family decisions
- v. Organizing a home visit
- vi. Meetings and evaluations

#### k- Assessment

- 1. Assessment of the child
  - a. Identify specific areas to be assessed
  - b. Develop a plan based on assessment

2- Assessment of the family

- c. Identify specific areas to be assessed
- d. Develop a plan of family support based on assessment

# 1- Reporting and evaluation.