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Families' Perceptions of Support Service Information for Young People with Hearing Loss: The Development and Validation of a New Measure

BY

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Abstract

The research reported here was concerned with the development and validation of an instrument that could be of value in studying the perceptions of the information about the support services (SS) provided to families with children or adolescents with hearing loss. SS are vital, flexible forms of assistance that can enhance the families' ability to care for their child or adolescent who has a hearing loss.

While several instruments and scales have been developed to facilitate studying the perceptions of information provided to families of children with and without special needs about various types of supports, data on such instruments concerned specifically with studying the perceptions of the information about SS provided to families with children or adolescents with a hearing loss are scanty. The broad aim of this study, therefore, was to develop and validate a new measuring instrument that would fill this void. Such an instrument would not only be of value in obtaining information from families about their views concerning the information they received about SS, but also it would have implications for intervention purposes. For example, a family's response obtained with the new measure could be used as a basis for discussion of the family's unmet information needs and planning the strategies for addressing these needs.

Following initial development, the instrument was reviewed for validity by a panel of SS experts and families with children with hearing loss. Following modification and a pilot trial, a field test with the final version of the instrument was conducted with 71 families with children with hearing loss. Results indicated that all the items on the instrument have high internal consistency reliability (>0.80). Given its high reliability, the new instrument is a potentially strong assessment tool of the perceptions of the information about SS provided to families with children with hearing loss.

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CHAPTER 1

INTRODUCTION AND BACKGROUND OF THE PROBLEM

The importance of incorporating information about support services (SS) in the management of hearing-impaired children (HIC) is well documented in the literature (Bradley, 1992; Pendergast, Lartz, & Fiedler, 2002). SS are flexible forms of assistance that should enhance a family's ability to care for a member with a hearing loss (Seltzer & Essex, 1998). With the current emphasis on keeping HIC and other children with disabilities with their families and the limited availability of residential services, there has been an increasing recognition that relevant information about SS must be available to assist family caregivers. Dale (1996) observed that information about SS is necessary in that families with HIC may be unaware of the services available that could be of assistance to them. Consequently, they may not be utilizing these SS for the benefit of their HIC and themselves. Clearly, information about SS can guide families with HIC to helpful resources in the community.

Bailey, Simeonsson, Winton, Huntington, Isbell, O'Donnel and Helm (1987) observed that the importance of providing information to families with HIC about SS is a recognized principle in service delivery. According to Bailey et al. (1987), information about available SS facilitates the involvement of families in the planning of intervention programs for their HIC. The involvement of families ensures that specific concerns about the needs of their

HIC are targeted in the intervention plan. The involvement of families in the planning and implementation of intervention programs for HIC is essential to achieving positive outcomes (Harley & Tice, 2002; Turnbull & Turnbull, 2001).

Evidence indicates that programs that have involved the members of the families of HIC in planning and implementing intervention have consistently achieved better outcomes for these children (Brown, 2001; Cherow, Dickman, & Epstein, 1999; Mittler, 1993). Indeed, it has been argued that the family must be recognized as the essential element if success is to be attained in any habilitation program for HIC (Downs, 1993). Downs considered that, unlike traditional programs that have addressed only the child's needs, the intervention team must now focus on the child within the ecological system of the family. The professional's goal must therefore address family-identified needs in a partnership between professionals and family members.

Further, the difficulties encountered by families in coping with the diagnosis of hearing loss in their children is one of the important justifications for providing information about support services to families with HIC (Luterman, 1991; Meadow-Orlans, 1995; Vernon & Andrews, 1990). Evidence indicates clearly that the diagnosis of hearing loss in a child can be very emotionally devastating to the parents (see for example, Densham, 1995; Kwok, 1995; Rodda & Grove, 1987; Scheetz, 2000). Desselle (1994) argued that information about SS could assist families with newly diagnosed HIC to learn about (1) the professionals available that can assist them to navigate through their feelings and reactions to the diagnosis of hearing loss, (2) the various implications of their children's hearing loss, and (3) how their appreciation and acceptance of their children's hearing loss affects the children's self esteem and development (pp. 322-328).

It is evident from the foregoing discussion that timely information about SS may not only result in early involvement of families in the care and management of HIC, it may also diminish the denial mechanism and other negative reactions to the diagnosis of hearing loss. Consequently, it is essential that families with HIC are provided information about SS following the diagnosis of hearing loss in their children.

Although the importance of providing information about SS for families is recognized in the literature, evidence indicates that, in many instances, such information is not provided to these families (Lane, Hoffmeister & Bahan, 1996; McConachie, 1996; Mittler, 1995; Robinshaw & Evans, 2001). It seems to be the case that while the importance of providing information about SS for families is acknowledged in policy statements, in practice many families with HIC or other children with special needs are not provided information about these SS.

It has been suggested that information about SS may not be provided to families because SS professionals tend not to be concerned for the family as a whole (Davis, Buchan, & Choudry 1994; Lane, et al. 1996). For instance, Davis, et al. (1994) observed that many service providers do not have the resources to adopt a family-centered or ecological approach in service delivery. The focus of service providers is directed to the child's disability and not on the needs and wishes of the parents and other family members and their strategies for coping, nor on the professional skills needed to provide family-centered services.

The failure to provide information about SS to families may have adverse consequences. For instance, a family's ability to adapt to their child's hearing loss may be hindered by the lack of information about SS. Evidence clearly indicates that the lack of or inadequate relevant information about SS remains a significant source of parental complaint (Cunningham, 1994; Mittler, 1995).

Purpose of the Study

It is evident from the preceding section that information about SS is crucially important to families with HIC. Nonetheless, there is no instrument, to this writer's knowledge, that could be utilized to assess the perceptions of the information provided to families with HIC about SS. Therefore, the purpose of the present study was to develop and validate a measuring instrument designed to obtain the views of families with HIC of the information provided to them about SS.

Clearly, there are several pressing concerns necessitating the provision of SS information to the families with HIC. Evidence indicates that approximately 94% of HIC become hearing impaired prelingually (i.e., before the age of three and/or prior to complete acquisition of the societal language), and 92% of these HIC have normally hearing parents (Center for Demographic Studies, 1984; Moores, 2001). The numerous formidable obstacles facing these families concerning the development of their HIC raise the need for information about SS. Consequently, the purposes of the present study were two-fold, namely:

1. To develop a measuring instrument designed to study the perceptions of families with HIC of the information provided to them about SS, and
2. To validate the new instrument utilizing a review panel of experts on SS and families with HIC, and by administering it to a sample of families with HIC.

Such an instrument would be of value in obtaining evidence from families about their reactions to the information provided to them about SS. In addition, the instrument could yield information that could be used by service providers to improve their services.

Definition of Terms

Support Services

The term “support services” (SS) as used in the study includes formal services provided to parents and other family members involved in the care of children with hearing loss. These services include counseling, communication and language development programs, early intervention programs, amplification devices, and educational programs, and communication options.

Family

The term “family” includes all persons who are closely involved with the care of children with hearing loss: parents, siblings, grandparents and, in some cases, foster parents.

Hearing Impairment

Hearing impairment is a generic term for any hearing loss regardless of the etiology or severity. The term is used without any suggestion of a deficit view of hearing loss, which places emphasis on the correction of perceived hearing disability (Lane, et al.1996; Rodda & Eleweke, 2000).

Hearing Loss

Hearing loss means a dysfunction in hearing acuity. The degree or extent of hearing loss ranges from mild, to moderate, to severe and profound. Hearing loss could occur during the prenatal, peri-natal, or post-natal stage of life. A discussion of the various causative factors of hearing loss is beyond the scope of this study.

Organization of the Study

The remainder of this dissertation is organized in five chapters. In Chapter 2 literature relevant to the study is reviewed. The review covers an overview of the useful outcomes of SS for families of HIC. Procedures in the development and validation of the new instrument are discussed in Chapter 3. In Chapters 4 and 5 activities and results concerned with the validation of the new instrument are reported. The summary, conclusions and implications of the new instrument for practice and research are discussed in Chapter 6.

CHAPTER 2

LITERATURE REVIEW

The review of literature begins with an overview of the importance of parental involvement in the development of hearing-impaired children (HIC). This overview is followed by a review of the useful outcomes of support services (SS) for families with HIC. The literature indicates that information should be available to families with HIC about important outcomes of SS such as (1) strategies for dealing with reactions to the diagnosis of hearing loss, (2) counseling and guidance, (3) opportunity for participation in early intervention programs, (4) fostering the educational development of HIC, and (5) empowerment of families through collaboration with SS professionals.

Parental Involvement and the Development of Hearing-Impaired Children

Evidence indicates that parental involvement in the provision of services for their HIC definitely influences, in positive ways, the children's development (Luterman, 1987; Martineau, Larmarche, Macoux, & Benard, 2001). It is therefore crucially important that families with HIC should be provided with the information about those services that are important for the development of many children.

The Family Systems Theory (FST), which explains what goes on within families when there are stressors such as having a child with a hearing loss or other special needs, illuminates the importance of providing information about relevant services to enable families to enhance the development of their children with special needs (Griffin & Greene, 1999; Shimoni & Baxter, 1996; Turnbull & Turnbull, 2001). The FST is the theoretical perspective that guides the present research. The desired outcome is to enhance family effectiveness and functioning by the provision of information relevant to the developmental needs of HIC. Roberts and Feetham (1982, p. 232) defined family effectiveness and functioning as "those activities and relationships among and between persons and the environment which in a combination enable the family to maintain itself as an effective system" in the presence of stressors such as having a child with a hearing loss. Each family member has perceptions of how well the family as a unit addresses certain tasks and challenges that the family needs to perform or meet successfully, such as caring for a member with a hearing loss. Factors having an impact on family functioning are (1) the family members' expectations, (2) the importance they assign to each function or challenge, and (3) their overall satisfaction with various tasks and relationships in the family unit (White, 1999, p. 233). Healthy family functioning occurs when the family unit interacts with its environment and fulfils various tasks and roles to maintain homeostasis. Effective family functioning is, therefore, a product of interactions with the community and support systems (macro level), and the relationships among family members (micro level) (White, 1999).

The influence of community services and support systems in enhancing the relationships within families having a member with a disability is well documented in the literature. Schlesinger and Meadows (1972) were among the earliest writers to discuss this. Utilizing Erikson's (1959) developmental stages, Schlesinger and Meadows illuminated the many influences of community services and support systems on the development of HIC. The parents and family members' grief over the diagnosis of the hearing loss, the lack of information on the developmental needs of the HIC, and confusing advice from professionals were some of the factors at the macro level that could have significant impacts on the development of HIC (Mindel & Feldman, 1987; Schlesinger & Meadows,1972).

Harvey (1989) and Harvey and Dym (1987) also applied the FST to deafness, and reported that dysfunction in families with HIC is the result of various macro level factors negatively affecting the HIC's micro level environment and not hearing loss itself. These authors stressed that factors in a HIC's environment must be considered from an ecological, non-linear perspective.

Griffin (1993) pointed out that FST suggests strategies that could facilitate altering the family's perspectives on the problem and their patterns of interaction in the presence of the problem so that the developmental needs of the child with hearing loss are effectively addressed. Griffin argued that if an intervention is to be effective for the HIC, then it must be recognized that families function as whole. Therefore the family should be treated as a whole.

The goal is to ensure treatment effectiveness by improving the quality of life for both the individual with the hearing loss and members of his or her family. Several FST proponents (for example, Bronfenbrenner, 1979, 1986; Gibbs, 1993; Stucky & Newbrough, 1983) have argued that a major function of the support services provided to families with HIC should be to facilitate effective interaction between the family members and the HIC. These authors considered that well-informed and well-supported family members can make incomparable contributions toward the fulfillment of the potential of children with hearing loss.

Meadow-Orlans (1995) observed that in recent years some service providers have been incorporating the FST in service delivery by changing their focus from providing services exclusively for the special needs of the child with a hearing loss to the provision of services for the full family unit. She argued that if intervention is to be effective for HIC, service providers must ensure that it takes place within the context of the family and community environments. Achieving this goal necessitates the recognition of the importance of a truly individualized intervention plan with information about SS for every family with HIC.

When the needs of family members are included in the service delivery plan, they will be able to work toward the success of the plan for the benefit of their child with hearing loss. This is because the family members have input into areas such as participation in formal planning and implementation of the program of care. They will also better appreciate the need to participate in advocacy and campaign for improvement in service provision for children with hearing loss either individually or as members of a family group (Luterman, 1991; Turnbull & Turnbull, 2001).

The importance of including the needs of families in the provision of SS for children with special needs has also been discussed by Blosser (1996). He observed that professionals cannot overemphasize the importance of developing meaningful relationships with all members of the family so that the family members could be exposed to relevant and appropriate information and "do-able" clinical strategies. By redefining and refining the contact with the families receiving services, professionals can increase the quality and quantity of the service delivery. Blosser (1996) supported the involvement of families on two important premises:

> First, individuals best improve and develop new skills if they are stimulated to do so during their daily routine. Second, persons in the individual's environment are often eager and able to assist in the treatment process and should learn how to do so.
> (p. 35).

The provision of support services that accommodate the needs of family members as well as those of the child with hearing loss is vital particularly during the children's pre-school years. During this time, the children spend most of their time with their families. Services provided at this stage have a significant impact on the children's social, emotional, linguistic, and intellectual development (Pendergast, et al. 2002). Therefore information about support services should be provided to parents to help them understand that their children's hearing impairment can have a significant impact on the children's development as well as on the families' well being.

It remains the case, however, that parents with HIC may not receive information about relevant services. Skelton (1996) studied how parents of HIC perceived support services provided within one local authority in England. His findings suggested dissatisfaction with some aspects of the services. Skelton (1996) reported that "Accessibility of some of the professional services is brought into question by some of the parents' responses. Most parents were unaware of, and so [were] unable to use the services of social workers for deaf people. Also parents complained about [difficulties with information and] access to the speech and language therapy services" (p. 78).

The literature indicates clearly that the needs of the family members of HIC are often not identified and addressed in SS provision. For instance, Martineau, et al. (2001) studied the nature of the services provided to 112 families with HIC in Quebec, Canada. One of the major findings of this study was that 68.4% of the total number of hours of intervention were child-centered compared to only 31.6% directed to parents.

Eleweke and Rodda (2000) conducted an in-depth study into the factors influencing the selection of communication mode used with HIC by parents. The results indicated that the families were dissatisfied with the process of diagnosis, counseling, and information about the developmental needs of HIC, and the services provided. It is evident from the results of these studies that family-centered services remain a small portion of all services provided to HIC.

The foregoing documentation of the importance of SS information for families of HIC raises the need for an instrument that could be used to obtain valid and reliable evidence about how families of HIC perceive the information provided to them about SS. This study was undertaken, therefore, with the aim of developing and validating a formal instrument that could be of value in meeting this important need.

Useful Outcomes of Information about Support Services

The provision of relevant and useful information about SS to families with HIC should produce useful outcomes for these families concerning the care and development of their children. This section addresses five important outcomes of SS information for families with HIC. These are:

- strategies for dealing with reactions to the diagnosis of hearing loss,
- developmental needs, counseling and guidance,
- opportunity for participation in early intervention programs,
- fostering the educational development of HIC, and
- empowerment of families through collaboration with SS

professionals.

Dealing with Reactions to the Diagnosis of Hearing Loss

The literature indicates that the provision of information about SS for families of HIC could assist the family members to obtain services that will enable them to deal in a positive manner with their varied intense and painful emotional reactions when they first learn that their child has a hearing loss. Evidence suggests that 92% of the parents of HIC have normal hearing and have no previous experience of hearing loss in the family (Eleweke & Rodda, 2000; Moores, 2001; White, 1999). Bodner-Johnson (2001) considered that being the hearing parents of a HIC means assuming a new role and a new set of responsibilities - a role the parents had not anticipated and for which they probably have had little preparation. The new responsibilities compete for time and attention with the other responsibilities in their lives, and in all likelihood introduce a sources of stress. Also a new orientation is now required - one that focuses on deafness. It is for this reason that information about the SS available is crucially important to these parents and other members of their families.

Marschark (1997) observed that the entire family is affected in one way or another by the stressful reactions to the diagnosis of the hearing loss. These reactions run the gamut from grief: (shock, denial, anger, guilt, depression, and anxiety) to coping: (containment of loss, reassessment of "normal" standards, enlarging scope of values, and shifting from "comparative" to "asset" values) (see, for example, Lane, et al, 1996; Luterman, 1991; Odgen, 1997; Vernon & Andrews, 1990). When dealt with appropriately, these reactions can be considered normal and healthy. Experiencing these reactions is necessary for the families to come to terms with the radical changes in their lives by the diagnosis of hearing loss of a child in the family. Dealing successfully with these emotional reactions enables members of the family to incorporate necessary changes into an adjusted worldview. If families are helped to successfully resolve these painful emotions and reactions by the provision of information about SS, they can then move into a position of strength that will enable members of the family to think more clearly and, perhaps, act more effectively in meeting the developmental needs of their HIC. The literature suggests that those family members who receive information about emotional and other SS from support groups consisting of other parents and professionals are best able to deal successfully with these painful reactions in particular and the demands of having a HIC (Calderon & Greenberg, 1999; Marschark, 1997; Powell, Batsche, Ferro, Fox, & Dunlop, 1997).

The need for information about SS that will educate families about childhood deafness and the special needs of the HIC that must be addressed to ensure optimum development have been stressed by several researchers. Calderon and Greenberg (1999), for instance, used a competence-based model of stress and coping in studying 36 hearing mothers of HIC. Information about and access to available social support emerged as an important predictor of maternal adjustment as well as a buffer between current life stress and maternal adjustment. Mapp and Hudson (1997) studied stress and coping strategies of 98 parents of HIC. The results indicated that parents reporting low levels of stress were those who received information and social support. Stress was further lowered for parents who received information and support that enabled them to learn sign language so that they could communicate fluently with their HIC. Lampropoulou and Konstantareas (1998) studied stress and parental involvement in 42 mothers of HIC. The results indicated that those mothers who received very little or no information about the developmental needs of their HIC and SS reported greater stress and were more likely to view their involvement in their children's development as more of a chore. The mothers reported few sources of information and support.

It is evident from the above discussion that relevant information can assist families with HIC in learning how to utilize available resources to cope positively with the diagnosis of hearing loss in their children.

Developmental Needs, Counseling, and Guidance Information

The provision of relevant information on the developmental needs of HIC is an important outcome of effective SS provision for families with HIC. The literature indicates that a major feature of effective SS is the provision of professional information or guidance to help family members become more informed about the condition of hearing loss. Parents and other family members need information about what hearing loss entails so that they will know what they can do to help their HIC to develop successfully.

It has been argued that making informed choices and decisions on many issues depends on adequate information (Welch, 1996). Evidence indicates that the provision of adequate information should enable the family members to make informed choices on whether to take up a service offer (Dale, 1996). In particular, during the time the hearing loss is diagnosed, it is vital that information about the child's condition and developmental needs be communicated to the parents and other family members in terms that can be understood and remembered.

It remains a challenge for SS practitioners to ensure that parents and other family members have access to all relevant information that will enable them to decide what is right and best for the HIC and themselves. The focus of information that professionals need to provide to parents should be on specialized knowledge of the child's condition, the characteristics of the condition, and some of the potential consequences and prognosis of the condition.

Although the importance of providing information about HIC's developmental needs as well as information about counseling and guidance to parents is well reported, the literature indicates that several factors limit the information provided to parents and other family members by service providers (Dale, 1996; Sussell, Korinek & Bullis, 1996). These factors include

(1) communication difficulties; (2) lack of a common base of knowledge by professionals and parents; (3) differences in the professionals' understanding of "models" and conceptions of disability, causality, and prognosis; and (4) family members' unfamiliarity with the medical vocabulary. The literature indicates that inadequate or total lack of information about hearing loss and what it entails remains a major concern of families with HIC (Gregory, Bishop & Sheldon, 1995; McCracken & Sutherland, 1991).

Thorburn (1994) identified several adverse consequences of the lack of information or the provision of misinformation to the parents and other family members of HIC. These adverse consequences are: (1) persistent misconceptions and superstitious beliefs about the cause of the disability, (2) ignorance of what can be done to help the child with a disability, and (3) shopping around for a remedy due to the misconception that a cure can be found or is possible by medication or traditional treatment if only the right practitioner could be found (p. 33). Further, Thorburn (1994) observed that rehabilitation measures may be delayed due to lack of information. The delay in initiating rehabilitation programs can greatly retard the development of the child with a hearing loss (Yohsinaga-Itano, 2000). Consequently, there can be poor expectations of the performance of HIC. Lower expectations of the performance of HIC can result in their isolation and denial of opportunities to learn. Deprivation of opportunities to learn subsequently leads to self-fulfilling prophecies of dependence and uselessness for these children.

In general, families' need for information about their children's developmental needs is a primary concern. For example, Peet (1995) examined the sources of information on the developmental needs of 3-year old normal hearing children by 62 parents. The results indicated that almost half of the parents reported depending on their own intuitions, religious beliefs, and childhood experiences as sources of information concerning the developmental needs of their children. While these sources of information could be useful, there is the possibility that stereotypical and superstitious beliefs, as well as other harmful practices, could be incorporated into such sources of information.

Chen and Simeonsson (1994) conducted a study involving 101 families of children with special needs. Families of children with hearing and speech impairment accounted for 62% of the sample. The findings indicated that the need for the provision of information about the children's developmental needs was considered as the most pressing need by the families.

These findings underline the immense need to provide information about sources that help parents cope with family problems, concerns, stress, and negative feelings so that a child with a hearing loss is integrated into the family with the least possible adverse effect on the functioning of the family. Consequently, a primary goal should be to develop sources for disseminating information about these children's developmental needs, formal, and informal family support services. With adequate information, parents may be able make decisions about services that address the developmental needs of their HIC. In addition, they will be able to make decisions about services that are responsive to family needs and which build on the unique resources of the family, the community, and culture of which the families are a part.

Participation in Early Intervention Programs

Early intervention refers to services provided to toddlers and infants 0-5 years in age who are deaf, hard of hearing, have other disabilities or special needs. (Turnbull, Turnbull, Shank, & Smith, 2004). These authors observed that early intervention programs are family-centered because at this stage of development the parents with HIC have many questions and concerns, for example, about communication methodology. Early intervention services help families and young children who have hearing loss to learn to communicate and to adjust to living with the hearing loss. Services may include assistance to families in developing communication with their children by information and instruction about different methods of communication (Turnbull, et al., 2004). Early intervention before the age of 5 has been shown to significantly affect the prognosis of children diagnosed with a hearing loss (Davis & Hind, 2003; Harrison, Roush, & Wallace, 2003; Moeller, 2000; Yoshinaga-Itano, et al. 1998).

The effectiveness of early intervention for HIC and other children with disabilities has been a critical area of inquiry for the past 25 years (Casto &

Mastropieri, 1986; Warfield, Hauser-Cram, Krauss, Shonkoff, & Upshur, 2000). Early intervention programs are essentially concerned with remediating existing developmental problems and preventing the occurrence of additional disabilities. Evidence indicates that children with hearing loss who received early intervention services have developmental advantages over comparison groups (Guralnick, 1998; Shonkoff & Hauser-Cram, 1987). Successful early intervention programs not only focus on the child's needs, but also on the needs of the family system in which the child is nurtured. Warfield, et al. (2000) studied the effectiveness of early intervention programs provided to 133 children with hearing loss and other disabilities and their families. Their results indicated that intensive early intervention was associated with developmental gains for the children and improved family cohesion.

The primary purpose of early intervention is to provide successful early learning experiences for young children with hearing loss or other special needs. Wilson (1998) argued that if success is to be achieved, early intervention programs must be implemented in an effective and timely manner. Further, he stated that early intervention could prevent or minimize the handicapping or at-risk condition from undermining the development and future capabilities of these children. Early intervention, therefore, has remedial and preventive values.

The involvement of parents and other family members of HIC is imperative for the success of any early intervention program (Turnbull &

Turnbull, 2001). A child's parents are considered the ultimate decision-making authority in the management of the child. Their full co-operation and participation is imperative for the success of early intervention programs (Turnbull, et al. 2004). Evidence suggests that the success of early intervention is dependent to a large extent upon the development of relationships between professionals and family members in which the family members assume an important role in assessment procedures and in the development and implementation of intervention programs (Allen, 1995).

The literature indicates that early intervention is the first step in the total management of a child with hearing loss. Early initiation of rehabilitative procedures in the management of HIC can ameliorate later potential adverse effects of the condition on the children's social, emotional, intellectual, and linguistic development (Haggard, 1992, 1993; NDCS, 1994; Robinshaw, 1995). Fortnum and Davies (1993, p. 43) observed that in some cases early intervention could (1) reverse the impairment though an operation or ameliorate the consequences of the hearing loss, (2) allow the hearing loss to be monitored, and (3) ensure that parents and professionals are made aware of the additional impact of any subsequent deterioration of the hearing loss. Boothroyd (1988) observed that countless numbers of HIC have had their developmental opportunities dramatically expanded by early intervention. This is particularly true of those children whose hearing loss were diagnosed before the age of six months through universal newborn hearing screening programs (see for example, Johnson, 2002; Kenna, 2003; Yoshinaga-Itano, 2000; Zochodne, Brown, & Dort, 2001). Some of these children have been transformed from deaf to hard of hearing by modern hearing aids, cochlear implants, and proper auditory management. Several recent studies indicate that cochlear implants, in particular, can enable some children with hearing loss to acquire good verbal communication skills (Kirk, Miyamoto, Lento, Ying, O'Neill, & Fears, 2002; Robbin, Bollard, & Green, 1999).

The importance of early intervention, particularly fitting hearing aids or other amplification devices, for HIC is well documented in the literature. Markides (1986) investigated the effect of the time of hearing aid fitting after detection of hearing loss on speech intelligibility. The results of his study indicated that speech intelligibility of those HIC who were detected and were fitted with hearing aids in the first six months of life as significantly superior to that of similar children who were fitted with hearing aids later in life. Ramkalawan and Davis (1992) also demonstrated the benefits of early hearing aid fitting for HIC. They investigated the oral language production abilities in 20 HIC with bilateral sensorineural hearing loss equal to or greater than 25 dB HL. They found significant correlations between the expressive language abilities of the HIC and the time of hearing aid fitting and other interventions following onset of hearing loss. Further, the results indicated that HIC who received early intervention services immediately after the diagnosis of hearing loss developed stronger expressive language abilities than those HIC who received early intervention services later. Ramkalawan and Davis (1992) concluded that early intervention for any hearing impairment, not just the profound losses, could be beneficial for a child, even if the degree of benefit varied with the severity of the hearing impairment. According to these authors, early intervention could be in the form of acoustic amplification, where applicable, and exposure to educational programs, encouraging maximal use of residual hearing and the development of language in whichever modality is judged most appropriate for the individual child in question.

The literature suggests clearly that the initiation of an intervention program as soon as possible after the onset of hearing loss can result in HIC acquiring language, emotional, social, and cognitive skills at the same rate as their normally hearing peers (Robinshaw, 1995). Watkin, Bechman, and Baldwin (1995) and Simeonsson (1991) observed that the families of HIC require information and support services to realize the benefits of early rehabilitation programs and to participate actively in these programs. Simeonsson (1991) considered that the growing recognition of the importance of early intervention for infants and young children with hearing losses and the involvement of the family members are factors which contribute to the conceptualization of services which are preventive in nature. This recognition parallels broader concerns for family support programs that have a preventive focus and seek to enhance the development of the children and families. These early intervention programs enhance development and minimize the potentials for delay, minimize the need for special education and related services, and minimize the likelihood of institutional or other restrictive care outcomes (Gabbard & Schryer, 2003; Li, Bain, & Steinberg, 2003). Eisermann and McCoun (1995) advocated that family members should be offered a broad range of information about SS and options that are available in the early intervention services and programs for their children. In order to achieve this goal, they suggested that professionals "must be prepared to assume a variety of roles including (a) assisting parents in making choices about their roles in intervention, (b) providing direct intervention with parents and (c) helping parents develop skills to implement interventions with their children" (p. 42).

Fostering HIC's Educational Development

Adequate information on SS would enable families to participate actively in the educational development their children. For instance, Guilford and Upton (1992) considered that information emphasizing the importance of close co-operation between home and school is essential for families. It facilitates decisions and strategies pertaining to the achievement of the following outcomes: (1) maintaining good personal relationships between parents and teachers, (2) understanding by parents of the aims and methods of the school, (3) offering opportunity for parents to contribute positively to the school's work, and (4) maintaining a two-way channel of communication with the child (p. 125).

Mba (1995) observed that information on the importance of parental participation in educational programs creates an increased awareness of the child's educational needs and increases the opportunity for home-school contact. He argued that adequate information on SS would provide the opportunity for parents to contribute directly to the education of their children.

The provision of the relevant information about the educational needs of the HIC to their family members is very important (Calderon, 2000; Luckner & Muir, 2001). According to these authors, a parent-teacher combination provides a powerful instrument by which to attain desired behavior in the child. This is because parents and teachers can develop rapport and plan programs (including revision of the curriculum) or any other alterations that may help the child with special needs to benefit from his/her learning situation. The provision of information to enhance parental participation in the education of their HIC is well-supported in the literature (Johnson, Liddel & Erting, 1989). Johnson, et al. maintained that in addition to enhancing their participation in HIC's educational development, such information also provides educational and emotional support for the family members of HIC. It enables the family members to come to grips with their children's developmental and educational needs and to be able to make the necessary adaptations to meet their children's developmental needs.

The literature indicates that educational outcomes for hearing-impaired students remain problematic (Easterbrooks, 1999; Holden-Pit & Diaz, 1998;

United States Department of Education, 1998). The low academic achievement of students who are deaf is well documented in the literature. For instance, the average high school graduate who is deaf reads at fourth- or fifth-grade level (Kluwin & Corbett, 1998; Lane, et al., 1996; Marschark, Lang, & Albertini, 2002; Schirmer, 2000). Implicated in this situation is the need for stronger parental participation in educational programs for HIC and the need for information about SS which emphasize the importance of early access to comprehensive language input for HIC.

Although the field has long recognized that parental involvement in early educational intervention programs is critical for positive educational outcomes for HIC (Mauk & Mauk, 1995), evidence suggests that due to lack of information, many parents with HIC have no regular and fruitful contacts with their children's schools (Morton, 2001). Morton (2001) observed that educators in school-based programs for HIC often decide on a child's placement, program, curriculum, and services without consulting the parents or care-givers.

Nonetheless, the literature has consistently indicated that the educational success of HIC is linked to the involvement of parents who are strongly committed to the development of good communication skills in their HIC as well as in the HIC's educational endeavors (Musselman & Kircaali-Iftar, 1996). It remains the case, however, that due to lack of information and limited parental involvement, many HIC do not have a useable language base either in English or American Sign Language by the time they begin formal education (Paul & Quigley, 1994; Rodda & Eleweke, 2000).

Relevant information about HIC's communication needs can make it possible for the family members to acquire sign language skills and thus be able to facilitate the child's language acquisition and communication skills development. The literature indicates that early exposure to sign communication facilitates HIC's linguistic, cognitive, social, emotional, and educational development (see for example, Andrews & Zmijewski, 1997; Drasgow, 1998; Padden & Ramsey, 1998).

The findings of Luckner and Muir's (2001) study of the factors contributing to the educational success of hearing-impaired students in general educational settings strongly support the need to provide parents with information that will encourage their participation in their HIC's educational development. Luckner and Muir (2001) interviewed 19 parents of deaf students. The parents considered that the information they received enabled them to contribute positively to their children's success in the schools. According to the parents, the information they received enabled them to fully appreciate the importance of their involvement and contribution to their children's success. They reported that the information they received enabled them to " ... seek additional speech therapy, learn sign language so they could communicate with their children, replace damaged hearing aids, and seek out additional opportunities so that their children could socialize with other children" (p. 438).

Empowerment through Collaboration with Professionals

The literature indicates that the most effective information about SS that could make the biggest differences in the lives of families and their children with or without special needs is the information that empowers family members (Briggs, 1999; Moghareeban & Banscum, 2000; Shankar, 2002). Turnbull and Turnbull (2001) described empowerment as knowing what the family members want, to have the motivation to strive to obtain it, and to have the knowledge and skills to turn their motivation into effective action.

Empowerment is best realized through collaboration with professionals such as the audiologists, speech and language therapists, psychologists, social workers, and teachers of the deaf (Norton, 1998). Collaboration is the process in which the expertise of the family is acknowledged by professionals and used in the selection, implementation, and evaluation of a program of treatment or rehabilitation (Sohlberg, McLaughlin, Toddis, Larsen, & Glang, 2001). Collaboration is, therefore, the sharing of resources among individuals, working jointly with others, and creating a context that enhances collective action. Through empowerment and collaboration family members strive to take control over their lives and try to take actions to get what they want for the good of their child.

Sohlberg et al. (2001) observed that although the skills required to create collaborative partnerships with families are the mainstay of practice for certain rehabilitation disciplines, others have traditionally worked in client-clinician dyads that emphasize the role of the professional in every aspect of the service delivery. Nonetheless, the literature indicates that the key elements of a family-centered rehabilitation program must include meaningful participation by families in decision-making and program implementation (Hostler, 1999).

Shimoni and Baxter (1996) considered that when properly organized and carried out, collaboration could be meaningful and effective in that important information is communicated in both directions, and parents and SS professionals can work together toward common goals. They outlined the important factors that influence the success of the collaboration endeavor. These factors include "...having a clear understanding of goals, having a repertoire of strategies and activities, considering the practical aspects before hand, and having in place some ways of evaluating the success of parental involvement on an ongoing basis" (p. 269).

Ahmann (1996) and Heflinger and Bickman (1996) observed that one of the key elements of family-centered services is meaningful family-professional collaboration or partnership, that recognizes that the family is the center of the provision of comprehensive care for the child. Heflinger and Bickman (1996) observed that through collaboration professionals and families contribute knowledge in determining what is in the best interest of the child and family. These authors considered that although professionals bring expertise in child development and the service delivery system, they often fail to realize that this knowledge is incomplete without the perspective of the parents, especially in formulating goals and implementing decisions related to the needs of the child.

Collaboration is therefore considered an essential aspect of SS provision for families of children with special needs in that it enhances a relationship in which family members and professionals work together to provide the best services for the child and family (Brown, 2001; DeChillo, Koren, & Schultz, 1995). In order to implement an effective collaboration or partnership model, it becomes imperative for professionals to alter the traditional service delivery process to include elements that can enable, empower, and strengthen families as well as promote acquisition of competencies necessary to meet the needs of the child and family.

Cantor and Cantor (1995) suggested the development and implementation of an Individual Family Service Plan (IFSP) as a means of achieving effective collaboration. The IFSP provides a mechanism for family members and the children with special needs to receive a well-planned and coordinated program for early intervention services (Allred, Brien, & Black, 1998; Bagdi, 1997). According to Cantor and Cantor (1995), a multidisciplinary team approach and family needs assessment will identify the family's unique needs. In the words of the Cantors: "Services appropriate to meet those needs will be identified. The IFSP will include the frequency, intensity, and methods of delivery of services. It also identifies a case manager who will be responsible for implementing the plan and coordinating with other agencies to make sure it is in place" (p. 107).

The variables that influence empowerment through collaboration between family members of children with special needs and SS professionals are extensive and complex. For instance, the way professionals conceptualize their practice may hinder effective collaboration (Crais, 1993; Easen, Atkins, & Dyson, 2000; File, 2001). Although collaboration is not always easy and is certainly time consuming, the rewards are great for individual professionals, young children with hearing loss, and their families (Briggs, 1999; Clifford, 1997). Stahlman (1994) suggested that effective collaboration could be achieved when SS professionals manifest an understanding of and sensitivity to both the unique concerns of families whose young children have hearing loss and the common concerns shared by most families.

The literature indicates clearly that the absence of collaboration between families with HIC and SS professionals can contribute to the failure to achieve goals. Harrison and Roush (1996) observed that lack of parental co-operation is a factor often cited by professionals for the failure of early identification and intervention programs. Bailey (1987) observed that if parents do not agree with or are not interested in the professionals' priorities for treatments, those treatments are doomed to failure. Therefore, according to Bailey (1987), by focusing on family priorities and by engaging in an open process of assessing, listening, and negotiating with families, professionals can create an interventionist-client relationship in which parents feel valued and through which professionals and families develop a mutual respect and understanding of each other's values and perspectives.

Evidence also indicates that effective collaboration has positive outcomes for the children with other special needs and their families. For instance, Vaughn, Dunlap, Fox, Clarke, and Bucy (1997) conducted a study of the effectiveness of professional-parent collaboration for a child with behavioral problems. The subject was a 9-year old boy with severe disabilities. A collaborative team including his mother designed and implemented a program of management and care. Although the study was limited to one case study, the findings were nonetheless significant. The results indicated reduced manifestation of problem behaviors and increased desirable mother-child interaction. In a related work, Haas and Roger (1995) conducted a case study of three language-delayed and language-disordered preschoolers. The results showed that the intervention program designed and implemented by professionals and the children's parents enhanced the development of new communication patterns in the children.

It is evident from the foregoing discussion that empowerment and collaboration may have the potential to enhance the families' understanding of the concept of choices in, for instance, communication methods with HIC and educational options, and can enable the professionals to assist families in finding needed services, agencies, and resources.

Summary

The literature indicates that information about SS may enable families with HIC to make decisions about those services that could (1) facilitate their adjustment to having HIC, and (2) enable them to meet the developmental needs of their children. Given the importance of SS information to families with HIC, the present study sought to develop and validate a survey questionnaire that could be utilized to obtain valid and reliable information about families' perceptions of the comprehensiveness, adequacy, and the meaningfulness of the information provided to them about SS. Once developed and validated, the information collected with the instrument could be used to:

- Promote awareness of the information needs of families with HIC,
- Stimulate interest and activity in the development of information sources about SS to meet the needs of families of HIC.
- Induce a re-appraisal of existing approaches to information-sharing with a view to determining effective ways of enhancing these approaches.
- Stimulate more research into provision of information to families with HIC in particular, and other families with special needs children in general.

CHAPTER 3

DEVELOPMENT AND VALIDATION OF THE NEW INSTRUMENT

> *Locally developed instruments, with no history of use or reviews by others, need to be evaluated [prior to their use in data gathering]... When researchers develop new instruments it is more important to gather appropriate evidence [for reliability and validity] and then report this evidence in the study*
>
> (Schumacher & McMillan, 1993, p. 226).

The above statement by Schumacher and McMillan (1993) succinctly captured the main objective of this study. In a nutshell, the objective of this study was to develop and validate an instrument that could be used to elicit reliable and valid evidence about the perceptions of SS information received by families with HIC. While several instruments and scales have been developed to facilitate studying the influences of various types of support for families with and without children with special needs (see for example, Bailey & Simeonsson, 1990; Child Development Resources, 1988; Darling, 1988; Dunst, Trivette & Deal, 1988; McCord, 1993; Summers, Turnbull & Brotherson, 1985), an instrument or scale concerned specifically with studying the perceptions and opinions of families with HIC about the support service information they receive is not, to my knowledge, available.

The need for research into the perceptions of families with HIC concerning the SS information they are receiving is an urgent one. The influx of young children identified through universal infant hearing screening programs and technological developments such as cochlear implants have established an urgent need for disseminating information about SS to families. Consequently, an instrument that yields information about the types and quality of SS information provided to families with HIC, that is reliable and valid, is needed. In this chapter, the procedures utilized in the development of the new measure and the procedures utilized in validating it are discussed.

Development and Validation of the Support Service Information Satisfaction Inventory (SSISI)

The items on the SSISI were generated following the sequence recommended by Crocker and Algina (1986, pp. 66-86). These procedures include: (1) determining the purposes for which the assessment from the SSISI will be used, (2) identifying and describing the outcomes indicative of good SS provision for families with HIC, (3) construction of an initial pool of items and methods of scoring, (4) review of the items in the SSISI by a panel of experienced SS professionals and families with children with hearing loss, (5) conducting a primary pilot trial on a sample of families of HIC and modifying the instrument as necessary, (6) field testing the SSISI on a larger sample of families with HIC, and (7) analyzing the data to estimate the reliability of the new instrument (pp. 66-82). Activities related to the first three steps are described in this chapter. Activities and results from steps Four and Five are discussed in Chapter Four. Activities and the results related to steps Six and Seven are discussed in Chapter Five.

Step 1: Purposes of Assessment with the SSISI

Crocker and Algina (1986) claimed that clarifying the purposes for which a new measuring instrument will be used greatly increases the likelihood that its final form will be useful for these purposes. The assessment obtained with the new instrument will have two main purposes. Firstly, the scores will produce data that can be validly and reliably interpreted in terms of the perceptions of families with HIC concerning the information they received about SS. Secondly, the results will have implications for intervention. A family's responses can be used as a basis for discussion of their opinions about the SS information provided to them, the availability of SS, or the appropriateness of SS relative to their specific circumstances.

Step 2: Identify and Describe the Outcomes of Good Information Provision about SS for Families with HIC

The review of the literature on SS (Chapter Two) generated five major areas that should be the focus of information about SS provided to families with HIC. These five areas include information about: (1) strategies for dealing with reactions to the diagnosis of hearing loss, (2) guidance and developmental needs, (3) opportunity for participation in early intervention programs, (4) fostering the educational development of HIC, and (5) empowerment of families through collaboration with SS professionals.

Step 3: Construction of the Initial Pool of Items

The needed information and the outcomes of effective SS identified in the literature research were used to develop 32 items that constitute the Support Service Information Satisfaction Inventory (SSISI). The distribution of these items across the five major areas is reported on Table 1. The detailed table of specifications used to develop the items is provided in Appendix A.

Table 1
Pool of Items in the First Draft of the SSISI

Support Service Outcome	Number of Items
Dealing with reactions to diagnosis of hearing loss	
Diagnosis	2
Coping strategies	2
Counseling	4
Guidance and Developmental Needs Information	
Communication needs	2
Sign language	2
Speech and language therapy services	2
Hearing aids	2
Assistive listening devices	2
Fostering Educational Development	
Education options	2
Deaf community	2
Empowerment, Collaboration and Utility	
Family support network	2
Collaboration, Usefulness and impact of support services	5
Professionals providing support services	1

Scaling and Polarities

Each item was accompanied by a series of seven-point evaluative scales associated with attributes of effective SS information. A seven-point scale format was used because it allowed for finer distinctions of participants' perceptions of the clarity, adequacy, understandability, and usefulness of the information. For example, the first two items on the instrument are shown below:

Diagnosis of Hearing Loss

1. Were you provided with information about the cause(s) of your child's hearing loss?
   _______ Yes _______ No (Please go to question 3)

2. How satisfied were you with the information about the cause(s) of hearing loss provided to you? Please circle the number that best reflects your satisfaction for each of the following four dimensions:

a. Very clear	1	2	3	4	5	6	7	Very unclear
b. Totally inadequate	1	2	3	4	5	6	7	Totally adequate
c. Not at all understandable	1	2	3	4	5	6	7	Very understandable
d. Very useful	1	2	3	4	5	6	7	Not at all useful

The seven-point scales were used to allow for a more accurate measurement of the full spectrum of participants' perceptions of SS information they had received. The scaling is appropriate for an instrument such as the SSISI, which is designed to survey the opinions and views of participants (Hittleman &

Simon, 1997; Neuman, 2000). This type of rating scale has been found to be reliable (Horne, 1985) and it yields a near-normal distribution (Kerlinger, 1986).

The polarities of the domains as shown on question 2 above were "flipped" or reversed in the instrument reviewed by the panel of experts, as well as in the final draft used in the field test. This was done so that the respondents would consider each question and their responses carefully thereby minimizing the problem of response bias. If the polarities were held constant, there existed the danger that some respondents might check all the high numbers without carefully considering the questions and responses. Consequently, it would not be possible to validly interpret the results. A copy of the first draft of the instrument is provided in Appendix B.

Methods for Validating the SSISI

The procedures utilized in validating the new instrument comprised: (a) a review for validity by a panel of SS experts and families with children with hearing loss, (b) a small-scale pilot trial on some families with children with hearing loss, (c) a field test on a larger sample of families of HIC, and (d) estimation of the internal consistency reliability of relevant items in the instrument using the Laboratory of Educational Research Test Analysis Package (LERTAP, Nelson, 2000). The first two procedures are discussed in Chapter Four and the last two are treated in Chapter Five.

CHAPTER 4

PANEL REVIEW AND PILOT TRIAL

A panel of three parents of children with hearing loss and seven professionals working with families of HIC or teaching in the area of deafness reviewed the first draft of the Support Service Information Satisfaction Inventory (SSISI). The panel assessed the items of the SSISI for content related-validity evidence. The selection of panel members to review the instrument was by purposive sampling (see Gay & Airasian, 2003 and Neuman, 2000 for an overview). The professionals were selected based on the following criteria: their deep knowledge and experience of providing services to families with HIC, directly or otherwise. Purposive sampling was appropriate for constituting the panel members because the professionals were in a special line of work, few and difficult to reach. Similarly, the parents with HIC had good experience of receiving services. Taken together, the reviewers were not many. However, the information concerning the experience and qualifications of the professionals and parents with HIC indicated clearly that they were knowledgeable and qualified to review the SSISI. The selection of the reviewers, qualifications of the reviewers, the process they followed, and the results of the review are presented in this chapter.

Selection of the Panel Members

The review panel included members who (a) provided support services or (b) received support services.

Service Providers

The professionals were selected based on their knowledge and expertise in the area of providing services, either now or in the past, to families of children with hearing loss. Some of the professionals were not providing direct services to families, but were teaching in the area of deafness. They had experiences related to the provision of SS. Altogether, 12 experts or professionals were invited to participate in the instrument review. The letter used to invite the professionals to participate in the review of the instrument is in Appendix C. The purpose of the SSISI as well as the function of the panel in the validation of the instrument were explained in the letter.

Seven of the professionals agreed to participate in the review. Three of the professionals indicated that they would not be able to participate due to their very tight and busy schedules. No responses were received from the two remaining experts.

Service Receivers

Seven families of children with hearing loss were invited through collaboration with an agency providing support services to families of children with hearing loss. It was essential that families of children with hearing loss participate in the panel since they would be main consumers of the SSISI. Three families responded in time and participated in the review.

Experience and Qualifications of Panel Members

The panel members' experiences and qualifications are summarized in Table 2. This information was obtained from the Experience and Qualifications Forms completed by the panelists (see Appendices E-i and E-ii). The first panel on Table 3 contains the summary for the professionals. The second panel contains the summary for the three parents. The three parents had received support services from different professionals.

Table 2
Sociodemographic Characteristics, Experience and Qualifications of Panel Members

A. Professionals (n=9)	n
Gender	
Male	2
Female	5
Hearing Status	
Hearing	5
Deaf	1
Hard of hearing	1
Age (Years)	
31 - 35	2
36 - 40	1
41 - 45	2
46 - 50	2
Professional Experience	
Teacher of the Deaf	2
School Administrator (Inclusive school)	1
Educational Consultant to schools	1
Professor, Assessment/Counseling	2
Preschool, Parent Program	1
SS Provision Experience (Years)	
0 - 5	0
6 - 10	2
11 - 15	2
>16	3
Level of Education	
Bachelor's Degree	1
Master's Degree	3
Doctoral Degree	3

(table continues)

Table 2
(continued)

B. Parents with HIC (n=3)	n
Gender	
Female	3
Male	0
Hearing Status	
Hearing	3
Deaf	0
Hard of hearing	0
Ages (Years)	
36 - 40	1
40 - 45	2
No. HIC in Family	
1	2
2	1
Ages of HIC (Years)	
0 - 5	1
6 - 10	1
11 - 15	1
>16	1
Experience Receiving SS (Years)	
0 - 5	1
6 - 10	1
>10	1
Level of Education	
High School/Equivalent	1
Diploma	1
Bachelor's Degree	1

Professionals

Five reviewers were males and two were females. Five of the professionals were normal hearing people, one was a deaf person, and the other was a hard for hearing person. They ranged in age from 31 to 49 years, with a mean age of 42.6 years. Three of the professionals worked as teachers of HIC; one was a school administrator (principal of an inclusive school that has deaf students); two others worked as instructors in deaf education, one of whom worked in the area of assessment, and the other worked in the area of counseling; and the seventh professional worked in a parent program for families of pre-school children with hearing loss. Their years of experience in the field ranged from 5 to 25 years, with a mean of 17.9 years. Three of the professional panel members had a Ph.D. in special and deaf education, one had a B.Ed. in deaf education, and three had a Master's degree in deafness rehabilitation.

Parents

All three 'family' reviewers were normal hearing mothers with HIC. The ages of the mothers ranged from 41 to 47 years, with a mean age of 43.0 years. There were two families with one HIC and one family with two HIC. The ages of their children with hearing loss ranged from 2 to 18 years, with a mean age of 8.5 years. The three parents had received support services from different professionals. The period they had been receiving support services ranged from 3 to 17 years, with a mean period of 8.3 years. One of the mothers completed high school, one had a diploma in political science, and the third had a B.Ed. in early childhood education. Considering the length of time they had been receiving support services, they were considered to be sufficiently experienced to participate in the review and validation of the instrument.

Meeting with the Panel Members

Five of the professionals and the three parents with HIC reviewed the instrument in a group meeting lasting approximately three hours. The two experts who did not attend the meeting completed the instrument alone. The instrument, forms specifying tasks in reviewing the instrument and the directions were sent to them. Pre-paid addressed envelopes were included for their convenience in returning the completed forms to this writer.

Although the five professionals and three parents with HIC met as a group, they worked individually in reviewing the instrument. Prior to reviewing the SSISI the panel members were warmly welcomed by this researcher and his advisor, Dr. Michael Rodda. The purpose of the panel review was explained to them. Their tasks in the validation process were described to them. They were requested to conduct a line-by-line review of the instrument as the first step in the overall validation process. The need for and importance of the new instrument were stressed. It was explained that there was a need for an instrument that could be of value in: (1) obtaining information from families of children with hearing loss on the information they received about support services, and (2) planning intervention programs. They were informed that a family's responses could be used as a basis for discussion of the family's unmet needs and planning to address these needs.

Prior to starting the review, the panel members were given the Consent Form (Appendix D-i) to read and sign if they wished to participate in the review. They were assured that their identities would be held in confidence and that no individual panel member's name would be mentioned in the thesis. In addition, they were assured that their comments and suggestions would be grouped into summary form and would be used only for the purpose of modifying the instrument. They were, therefore, encouraged to be free and honest in their review of the instrument and to not worry about their comments being identified and their names mentioned. All of them accepted and signed the consent form.

Specification of the Main Task of the Panel Members

The item-by-item review by the panel focused on: (1) the appropriateness, and (2) the relevance of the items. The panelists were asked to critically review the instrument (Appendix B) using the Table of Specifications (Appendix A) by completing the forms:

- Relevance and Representativeness, 2R Factor (Appendix F)
- Main Features Rating (Appendix G)
- Item Content Review (Appendix H-i and H-ii)

Results of Panel Members Review

Item Content Review

Using the Table of Specifications (Appendix A), the reviewers completed the Item Content Review Form (Appendix H-i and H-ii). The task of the reviewers was to judge the degree of fit between the items in the instrument and the domains to which they referenced using a five-point scale: 1-poor----5-excellent. The degree of agreement among the judges was examined. The summary statistics used in the examination of the degree of agreement was the judges' discrepancy from the median (JDM) (Rogers, 2000). The JDM for each of the judges is calculated by summing up the differences between each judge's score on the 75 items on the instrument and the median score for each item by all the judges. The formula for calculating each JDM is:

$$\sum_{k=1}^{75} \left| X_{ki} - Md_k \right| ,$$

where, X_{k1} = score given to item k by judge i, and Md_k = the median score for each item.

Eight (8) of the ten reviewers appropriately completed the form to enable the calculation of JMD. Two of the reviewers (a professional and a parent) did not complete the task. They did not rate all the items. The reasons for their failing to rate all the items were unknown. These two judges were therefore eliminated in the analysis. The calculation of the degree of agreement among the remaining 8 judges is presented in Table 3.

Table 3

Summary of Judges' Ratings/Discrepancy from the Median

Item	J1	J2	J3	J4	J5	J6	J7	J8	Mean	Med.
1	5	5	5	4	2	5	5	4	4.3	5.0
2 a	5	5	5	5	3	5	5	5	4.7	5.0
b	5	5	5	5	3	4	4	5	4.5	5.0
c	5	5	5	4	3	4	5	5	4.3	5.0
d	5	5	5	5	3	4	5	5	4.5	5.0
3	5	5	5	4	4	5	5	5	4.7	5.0
4 a	5	5	5	1	4	3	5	4	3.8	4.5
b	5	4	5	4	4	3	5	4	4.2	4.0
c	5	4	5	4	4	2	3	5	4.0	4.0
d	5	4	5	4	4	2	4	5	4.0	4.0
5	5	5	5	5	4	5	4	5	4.8	5.0
6 a	5	3	5	5	4	3	5	5	4.2	5.0
b	5	3	5	3	4	3	5	5	3.8	4.5
c	5	5	5	3	4	4	5	5	4.3	5.0
d	5	5	5	5	4	5	4	4	4.8	5.0
7	5	4	3	1	4	5	4	4	3.7	4.0
8 a	5	4	3	1	4	5	5	4	3.7	4.0
b	5	4	3	1	4	3	5	4	3.3	4.0
c	5	4	3	1	4	4	5	5	3.5	4.0
d	5	3	3	5	4	5	5	5	4.2	5.0
9	5	5	5	5	4	5	5	4	4.8	5.0
10a	5	5	5	3	4	5	5	5	4.5	5.0
b	5	5	5	5	4	5	5	5	4.8	5.0
c	5	5	5	4	4	5	5	4	4.7	5.0
d	5	5	5	5	4	5	5	5	4.8	5.0
11	5	5	5	5	3	5	4	5	4.7	5.0
12a	5	5	5	4	4	5	4	5	4.7	5.0
b	5	5	5	1	4	5	5	5	4.2	5.0
c	5	5	5	4	4	5	5	5	4.7	5.0
d	5	5	5	4	4	5	5	5	4.8	5.0
13	5	5	5	5	4	5	5	5	4.8	5.0
14a	5	4	5	4	4	3	5	5	4.2	4.3
b	5	4	5	5	4	4	5	5	4.5	5.0
c	5	5	5	1	4	5	5	5	4.2	5.0
d	5	5	5	5	4	5	5	5	4.8	5.0
15	5	5	5	5	3	5	5	4	4.7	5.0

(table continues)

Table 3 (continued)

Judges' Ratings

Item	J1	J2	J3	J4	J5	J6	J7	J8	Mean	Med.
16 a	5	5	5	4	3	5	5	4	4.5	5.0
b	5	5	5	1	3	5	5	4	4.0	5.0
c	5	5	5	4	4	3	5	5	4.3	5.0
d	5	5	5	5	4	5	5	5	4.8	5.0
17	5	5	5	5	4	5	5	5	4.8	5.0
18 a	5	5	5	5	4	5	5	5	4.8	5.0
b	5	5	5	1	4	5	5	4	4.2	5.0
c	5	5	5	4	4	3	5	5	4.3	5.0
d	5	5	5	5	4	3	5	5	4.5	5.0
19	5	5	5	5	4	5	5	5	4.8	5.0
20 a	5	5	5	5	4	5	5	5	4.8	5.0
b	5	5	5	5	4	5	5	5	4.8	5.0
c	5	5	5	5	4	5	3	5	4.8	5.0
d	5	5	5	5	4	5	5	5	4.8	5.0
21	5	5	4	5	4	5	3	5	4.7	5.0
22 a	5	5	4	1	4	5	4	5	4.0	4.5
b	5	4	5	5	4	5	4	5	4.7	5.0
c	5	4	5	5	3	5	5	5	4.5	5.0
d	5	4	4	5	4	5	5	5	4.5	5.0
23	5	5	5	5	3	5	5	4	4.7	5.0
24 a	5	5	5	4	3	5	5	5	4.5	5.0
b	5	4	5	1	3	5	5	5	3.8	5.0
c	5	5	5	4	3	4	5	5	4.3	5.0
d	5	5	5	5	3	4	5	5	4.5	5.0
25 a	5	5	5	5	3	5	5	5	4.7	5.0
b	5	5	5	1	3	5	5	5	4.0	5.0
c	5	5	5	5	3	5	5	5	4.7	5.0
d	5	4	5	4	3	5	5	5	4.3	5.0
e	5	5	5	4	3	5	4	5	4.5	5.0
f	5	5	5	5	4	5	4	5	4.8	5.0
26	5	5	5	5	4	5	4	5	4.8	5.0
27	5	5	5	4	4	5	4	5	4.7	5.0
28	5	5	5	5	4	5	5	5	4.8	5.0
29	5	5	5	5	4	5	5	5	4.8	5.0

(table continues)

Table 3 (continued)

Judges' Ratings

Item	J1	J2	J3	J4	J5	J6	J7	J8	Mean	Med.
30	5	5	5	5	4	5	5	5	4.8	5.0
31	5	5	5	3	4	5	5	5	4.5	5.0
32 a	5	5	5	5	5	5	4	5	5.0	5.0
b	5	5	5	1	5	5	4	5	4.3	5.0
c	5	5	5	3	5	5	5	5	4.7	5.0
d	5	5	5	3	5	5	5	5	4.7	5.0
e	5	5	5	4	5	5	5	5	4.8	5.0
f	5	5	5	4	5	5	5	5	4.8	5.0
g	5	5	5	5	4	5	4	4	4.6	5.0
h	5	5	5	5	4	5	4	4	4.6	5.0
i	5	5	5	5	4	5	5	5	4.9	5.0
JDM	9	13	13	81	92	28	28	16		

According to Rogers (2000), ideally, there should be a perfect agreement among the judges on all the items. In the ideal case, each judge's discrepancy from the median will be zero. However, due to differences in perspectives and levels of understanding, it is not realistic to expect the agreement of the judges on all the items to be perfectly identical.

Examination of the JDM indicated that six of the judges rated the items quite consistently. Judges 4 and 5, professionals, rated the items different from the other six judges. Judge 4 had a JDM of 81 and Judge 5 had a JDM of 92. The JDM of the other six judges were 9, 13, 13, 28, 28, 16 respectively. These six judges were more consistent, suggesting a better understanding of their task here. It might be that the Judges 4 and 5 were different from the other judges due to not properly comprehending the task. These two judges had argued that the switching of polarity in the instrument was confusing. This writer explained that the switching of polarities was necessary to make people think of the items thoroughly and not just circle all high numbers. Nonetheless, it might be the case that the two judges did not carefully consider the polarities and hence their very different ratings. Judges 4 and 5 were eliminated in the item analysis described in the next section. These judges had to be eliminated because they had rated the items quite differently from the other judges. If these two were not excluded in the item analysis, the results would be distorted (Rogers, 2000).

Item Ambiguity

Item ambiguity was assessed by looking at the range, R, of the judges' ratings for each item. For any item, k,

$$R_k = X_{kjH} - X_{jkL} + 1,$$

where X_{kjH} and X_{jkL} are, respectively, the highest and lowest rating for that item. For example, for item 1, the item ambiguity is 5-4+1 = 2. The item ambiguity of all the items on the instrument as rated by the 6 more consistent judges is shown in the last column in Table 4.

Table 4

Summary of Judges' Ratings and Item Analysis

Item	J1	J2	J3	J6	J7	J8	Med.	R
1	5	5	5	5	5	4	5	2
2 a	5	5	5	5	5	5	5	1
b	5	5	5	4	4	5	5	2
c	5	5	5	4	5	5	5	2
d	5	5	5	4	5	5	5	2
3	5	5	5	5	5	5	5	1
4 a	5	5	5	3	5	4	5	3
b	5	4	5	3	5	4	5	3
c	5	4	5	2	3	5	4.5	4
d	5	4	5	2	4	5	4.5	4
5	5	5	5	5	4	5	5	2
6 a	5	3	5	3	5	5	5	3
b	5	3	5	3	5	5	5	3
c	5	5	5	4	5	5	5	2
d	5	5	5	5	4	4	5	2
7	5	4	3	5	4	4	4	3
8 a	5	4	3	5	5	4	4	3
b	5	4	3	3	5	4	4	3
c	5	4	3	4	5	5	4	3
d	5	3	3	5	5	5	5	3
9	5	5	5	5	5	4	5	2
10a	5	5	5	5	5	5	5	1
b	5	5	5	5	5	5	5	1
c	5	5	5	5	5	4	5	2
d	5	5	5	5	5	5	5	1
11	5	5	5	5	4	5	5	2
12a	5	5	5	5	4	5	5	2
b	5	5	5	5	5	5	5	1
c	5	5	5	5	5	5	5	1
d	5	5	5	5	5	5	5	1
13	5	5	5	5	5	5	5	1
14a	5	4	5	3	5	5	5	3
b	5	4	5	4	5	5	5	2
c	5	5	5	5	5	5	5	1
d	5	5	5	5	5	5	5	1
15	5	5	5	5	5	4	5	2

(table continues)

Table 4 (continued)

Judges' Ratings

Item	J1	J2	J3	J6	J7	J8	Med.	R
16 a	5	5	5	5	5	4	5	2
b	5	5	5	5	5	4	5	2
c	5	5	5	3	5	5	5	3
d	5	5	5	5	5	5	5	1
17	5	5	5	5	5	5	5	1
18 a	5	5	5	5	5	5	5	1
b	5	5	5	5	5	4	5	2
c	5	5	5	3	5	5	5	3
d	5	5	5	3	5	5	5	3
19	5	5	5	5	5	5	5	1
20 a	5	5	5	5	5	5	5	1
b	5	5	5	5	5	5	5	1
c	5	5	5	5	3	5	5	3
d	5	5	5	5	5	5	5	1
21	5	5	4	5	3	5	5	3
22 a	5	5	4	5	4	5	5	2
b	5	4	5	5	4	5	5	2
c	5	4	5	5	5	5	5	2
d	5	4	4	5	5	5	5	2
23	5	5	5	5	5	4	5	2
24 a	5	5	5	5	5	5	5	1
b	5	4	5	5	5	5	5	2
c	5	5	5	4	5	5	5	2
d	5	5	5	4	5	5	5	2
25 a	5	5	5	5	5	5	5	1
b	5	5	5	5	5	5	5	1
c	5	5	5	5	5	5	5	1
d	5	4	5	5	5	5	5	2
e	5	5	5	5	4	5	5	2
f	5	5	5	5	4	5	5	2
26	5	5	5	5	4	5	5	2
27	5	5	5	5	4	5	5	2
28	5	5	5	5	5	5	5	1
29	5	5	5	5	5	5	5	1

(table continues)

Table 4 (continued)

Judges' Ratings

Item	J1	J2	J3	J6	J7	J8	Med	R
30	5	5	5	5	5	5	5	1
31	5	5	5	5	5	5	5	1
32 a	5	5	5	5	4	5	5	2
b	5	5	5	5	4	5	5	2
C	5	5	5	5	5	5	5	1
D	5	5	5	5	5	5	5	1
E	5	5	5	5	5	5	5	1
f	5	5	5	5	5	5	5	1
g	5	5	5	5	4	4	5	2
H	5	5	5	5	4	4	5	2
I	5	5	5	5	5	5	5	1

The value of R_k should ideally be 1. That is the highest and lowest ratings should be the same (Rogers, 2000). However, achieving an R-value of 1 for all the items is not realistic due to differences in levels of understanding and perception of the reviewers. R-values of 1 to 3 are considered acceptable. Examination of Table 4 indicates that all the items on the instrument except item 4c (adequacy) and 4d (usefulness of the information about strategies for coping) had acceptable R values. Items 4c and 4d had R value of 4, indicating ambiguity among the judges for these two items. In considering whether to eliminate these items from the instrument, the ratings of the individual judges were examined. For both items, Judge 6 rated the relevance as 2. Items 4c and 4d had an R of 4 because of only Judge 6. Of the remaining judges, three rated these items as "Excellent"(5) and two rated them as "Very Good" (4). These items were therefore retained. If the high R-values were due to ratings by the majority of the judges, these items would have been modified or removed from the instrument.

Item Relevance

Examination of Table 4 indicates that the median rating for each of the items on the instrument ranged from 4 (Very Good) to 5 (Excellent). This indicates that all the items were considered good fit by the judges.

Relevance and Representative-ness (2R Factor) and Main Features Rating

Table 5
Essential Features Rating

Question		n
The instrument incorporates relevant outcomes of support services for families with HIC	Yes	10
	No	0
The instrument incorporates essential outcomes of support services	Yes	10
	No	0
The content of the instrument is comprehensive	Yes	6
	No	4
All the items in the instrument should be retained	Yes	10
	No	0
I agree with the sequencing of the instrument	Yes	10
	No	0
The items in the instrument are clear and unambiguous	Yes	10
	No	0

The 10 reviewers appropriately completed the Essential Features Rating Forms (see Table 5). Based on the results presented in Table 5, the 32 items on the instrument were considered to incorporate appropriate information about support services provided for families with HIC. The reviewers were all in agreement that the essential domains and outcomes of support services for families of children with hearing loss were adequately represented by the 32 items. However, 4 panelists suggested that there were 3 additional aspects of SS for families with HIC that needed to be considered. They recommended that the following three aspects be added:

* Funding resources for families
* Informal - peer (families of deaf children) support networks
* Cochlear implants

Summary of Changes

Comments and recommendations of the panel members resulted in some changes to the instrument. An outline of the modifications is given below:

* Inclusion of a question on funding resources.
* Inclusion of a question on informal support networks.
* Inclusion of a question on cochlear implants.

The modified form became the final instrument (see Appendix I) for field testing. Prior to the field-testing, a pilot test was conducted as described below.

Pilot Test

The modified instrument was pilot tested with families of HIC whose children were receiving services from two educational institutions (K-12) for

HIC. The pilot test was to assist in further refining the items in the SSISI. A letter (see Appendix J) and consent form (Appendix D-ii) were attached to the instrument encouraging the parents to make comments and suggestions concerning directions, recording procedures, and specific items in the new instrument. Feedback from the pilot trial was to be used to revise items and questions that (1) were unclear, (2) did not elicit the desired information, or (3) produced negative reactions from the participants. Although the instrument was sent to 25 families with HIC, only 13 of the instruments were appropriately completed.

The 13 parents did not recommend any change to the instrument. However, two parents made comments about the need to include open-ended questions. Open-ended questions had not been included in the SSISI because it was expected that after it had been validated service providers would discuss a family's responses to the instrument with the family and obtain more detail concerning any aspect of support service needs of the family.

One parent wondered why the polarities were switched. The reason for switching the polarities was to make the respondents think carefully before making their responses. If the polarities were uniform, some respondents may just circle or tick all the high numbers, without taking the time to think the questions over thoroughly.

No further changes were made. The instrument was therefore field tested on a larger number of families with HIC. The procedures followed and the results obtained from the field test are described in the next chapter.

CHAPTER 5

FIELD TEST AND RESULTS

Following completion of the panel review and pilot test, the revised SSISI was field tested. The procedures followed to complete the field test and the results are reported and discussed in this chapter.

Target and Accessible Population

The target population for the field test comprised families with children and young people with hearing loss. Families of HIC, as the consumers of SS, were important for the validation of this instrument, which seeks their views, opinions, perceptions, and degree of satisfaction with SS information they received. The accessible population consisted of families with HIC in Edmonton, Calgary, Red Deer, and Leduc in Alberta, Canada; and Muncie, Fort Wayne, Hew Haven, and Indianapolis in Indiana, the United States.

Sample

A letter (see Appendix K) was sent to directors of three educational institutions seven itinerant teachers of the deaf, five educational consultants to schools, and four agencies providing services to families with HIC in these locations. The educational institutions were a residential school for the deaf, a special school for the deaf, and a regular school with a unit for students who are deaf or hard of hearing. The agencies included a division in rehabilitation hospital that provides audiology and speech therapy services to families with HIC, an agency providing counselling, amplification and assistive listening devices to families with HIC, and two different businesses providing audiology, speech therapy, and related services to families with HIC. The letter explained the purpose of the study and requested their permission and assistance in administering the instrument to families with children or adolescents who have hearing loss.

One educational institution, five itinerant teachers of the deaf, two educational consultants, and one support service provision agency agreed to assist with transmitting the instrument to families with HIC. Packets containing a cover letter (Appendix L), the Informed Consent Form (Appendix D-iii), instrument (Appendix I), and postage-paid return envelopes were sent to families with HIC through the above-mentioned agents. The consent form and cover letter assured the families of the confidentiality of information they provided as well as soliciting their cooperation in filling the instrument. The instruments were numbered for identification purposes.

The instruments were left with the educational institution, itinerant teachers, education consultants, and SS agency to be distributed to the families of HIC with whom they were in contact. This procedure ensured that the families maintained anonymity while participating in the study. After approximately two weeks, follow-up letters (Appendix M) and the instrument were sent to the families through the educational institution, itinerant teachers, educational consultants, and SS agency. The return rates of the instrument are shown in Table 6.

Table 6
Instrument Return Rate

Agency	# Sent	# Returned	%
Educational Institution	56	34	60.7
Consultants	15	6	40.0
Itinerant Teachers	25	16	64.0
Educational SS Provider	25	15	60.5
Total	121	71	58.7

The return rate of the instrument was encouraging considering evidence indicating that the return rate of mailed instruments is typically 20 to 30 percent (Christensen, 1994; Fowler, 2001). The overall return rate of 58.7% achieved in the present study exceeded the typical return rate reported in the literature and compares well with the return rate achieved in similar studies. For instance, in a study examining the views of parents with HIC of the information they received about educational options, the response rate was 36.4% (Bernstein & Martin, 1992). In a related study, Mukari, Vandort, Ahmad, Saim, and Mohammed (1999) examined parents' awareness and knowledge of the special needs of their HIC. The return rate of their mailed survey was 62.1%.

Data Entry and Analysis

The data entry was very carefully conducted to ensure that the data were correctly entered. To verify that the data were correctly entered, a statistician at the Center for Research in Applied Measurement and Evaluation in the Department of Educational Psychology, University of Alberta, and two evaluation and measurement professors at Ball State University, Indiana collaborated with this writer during the data entry stage. A printout of the data entered for each of the 71 participants was carefully examined against the questionnaire completed by that participant. Any discrepancy was thereby identified and corrected.

The statistical analyses were conducted using the frequencies program within the Statistical Packages for the Social Sciences (SPSS 11.0). The frequency of responses, the percentages, and cumulative percentages for each item were computed.

Demographic Description of the Sample

The demographic characteristics of the sample are summarized in Table 7. The data show that 58 (81.7%) of the parents indicated that they had normal hearing, eight (11.3%) described themselves as deaf, and five (7.0%) indicated they were hard of hearing.

Table 7

Demographic Characteristics of Families and HIC (n = 71)

Parents Characteristics	n	%
Hearing Status		
Hearing	58	81.7
Deaf	8	11.3
Hard of hearing	5	7.0
Experience of SS		
Receiving SS	71	100
Time received SS after diagnosis		
Immediately	29	40.8
1 - 5 months	20	28.2
6 - 10 months	11	15.5
11 - 15 months	9	12.7
>16 months	2	2.8
Professionals providing SS		
Audiologists	71	100
Teachers of the deaf	68	95.8
Speech/Language Therapists	53	74.6
Sign language Interpreters	47	66.2
Regular school teachers	46	68.4
Teacher Aides	27	38.0
Psychologists	27	38.0
Social Workers	24	33.8
Educational consultants	19	26.8
Education Assistants	16	22.5
Rehabilitation specialists	14	19.7
Other Professionals	9	12.7
Hearing Status of child(ren)		
Deaf	63	88.7
Hard of hearing	8	11.3
Current Age (years)		
0 - 6	3	4.2
7 - 12	53	78.9
>13	15	6.9
Age of Diagnosis (months)		
0 - 12	23	32.2
13 - 24	20	28.0
25 - 36	17	23.8
>36	11	15.4

This finding is consistent with findings of previous research indicating that over 80 percent of children and young people with hearing losses have normal hearing parents (Center for Demographic Studies, 1984; Moores, 2001).

All the parents indicated that they had received support services (SS). Of the 71 parents, 29 indicated that they had received SS immediately after the diagnosis of hearing loss in their children, 31 (43.7%) indicated that they had received SS within 10 months following the diagnosis of hearing loss in their children, and 9 parents reported they had received SS between 11 and 15 months after diagnosis. Two parents indicated waiting for 20 and 24 months after the diagnosis of hearing loss before they received services.

The parents indicated that the two most frequent sources who provided SS were audiologists (100%) and teachers of the deaf (98.5%). Approximately three-quarters of the parents indicated that they received SS from speech and language therapists (74.6%), while approximately two-thirds indicated that they received SS from sign language interpreters (66.2%) and regular school teachers (64.9%). Other less frequent sources of SS were psychologists (38.0%), social workers (33.8%), educational consultants (26.8%), special education assistants (22.5%), and other professionals such as pediatricians (12.7%).

Sixty-three (88.7%) of the young people with a hearing loss were "deaf," and eight (11.3%) were "hard of hearing." The majority of the children (78.9%) were between 7 and 12 years of age at the time of the study. Of the remaining 18, three (4.2%) were less than 6 years of age, and fifteen (6.9%) were over 13 years of age.

The age of diagnosis decreased with increasing chronological age. Twenty-three (32.2%) of the children were diagnosed before their first birthday, 20 (28.0%) during the next year, 17 (23.8%) during the third year, and 11 (15.4%) after their third birthday.

The finding that hearing loss was not diagnosed until after age two for two out of every five children is of concern. Previous researchers have found that HIC diagnosed this late in life frequently do not have access to early specialized services mainly because of the late diagnosis of their hearing loss (Craig, 1992; Meadow-Orlans, 1987; Strong & Clark, 1992, Watkins, 1987; Yoshinaga-Itano, 2000). Early diagnosis of hearing loss is critical to the linguistic, educational, social and emotional development of HIC (Marschark, 1998; Pendergast, Lartz, & Fiedler, 2002). Despite the knowledge that early diagnosis and intervention benefit a child with a hearing loss, the age of diagnosis and provision of services to assist children with hearing loss and their parents remains unacceptably high (Harrison & Roush, 1996; Kittrell & Arjmand, 1997; Marschark, 1998). Harrison and Roush (1996) found that the mean age of identification for children with no known risk factors was 13 months for HIC with severe to profound losses, and 22 months for HIC with mild to moderate losses. In a study of 291 HIC, Kitrell, and Arjmand (1997) found the average age of identification to be 20.2 months of age. In a recent study of 77 families with HIC, Pendergast, Lartz, and Fiedler (2002) found that the average age of diagnosis was 14.6 months. Pendergast et al. (2002) suggested that late diagnosis was often attributed to failure of physicians to investigate the possibility of hearing loss following suspicion by parents. It is clear from these findings that there is a need for physicians, audiologists, and related professionals to enhance their awareness of childhood deafness and to develop guidelines for the medical evaluation of suspected cases of childhood hearing loss to ensure prompt detection of hearing loss and the provision of support services.

Summary of Response Frequencies and Statistics

The respondents were asked to describe their perceptions of information about 16 aspects of support services. Table 8 contains a summary of their responses. This summary includes the number (N) of parents who responded to each set of 4 items for each of the 16 aspects of SS, the mean and standard deviation of their responses, and the value of Cronbach's alpha which reflects the consistency with which the parents responded to the items.

Table 8
Summary of Statistics

Information Domain	N	Mean	Std.Dev.	Coefficient Alpha
1. Cause of hearing loss	49	15.4	5.9	0.91
2. Coping strategies	18	17.1	5.6	0.93
3. Counseling for Parents	24	19.7	6.5	0.94
4. Counseling for others	12	16.8	8.6	0.98
5. Communications needs	59	21.7	4.9	0.90
6. Sign Language course	45	23.8	4.2	0.81
7. Speech/Language Therapy	45	17.8	6.1	0.88
8. Hearing Aids	65	22.5	4.8	0.91
9. Cochlear Implants	33	15.2	6.4	0.93
10. Assistive listening Aids	39	23.8	4.4	0.92
11. Education options	59	22.3	5.7	0.89
12. Funding resources	29	17.8	6.7	0.82
13. Deaf Culture/Community	28	23.6	4.3	0.81
14. Supportnetwork - Informal	13	19.8	6.0	0.98
15. Supportnetwork - Formal	26	22.6	4.7	0.93
16. Collaboration	71	30.8	7.3	0.89

The number of parents indicating that they had received information about the 16 aspects of support services varied across each support service aspect. The number ranged from 12 (counseling information for other family members) to 71 (collaboration with service providers). The means of their perceptions ranged from a low 15.2 (cochlear implants) to a high 30.8 (collaboration). The variation among the means reflects the different perceptions of the parents who had received information about support services. The median number of parents that indicated that they received information about these aspects of support services was 36 (50.7%). This means that half of the parents had received information about all the 16 aspects of support services. Inspection of the statistics reveals that the 16 aspects had an acceptable level of internal consistency, ranging from 0.81

to 0.98 (Mertens, 1998). This provides initial evidence that the instrument worked properly in that the respondents were consistent in their response to each set of items. This indicates that the instrument can be used to collect reliable data.

To further clarify the variation shown in Table 8, each aspect of support service information is discussed below. Each discussion is based upon the distribution of responses to the seven-point scale used (see Table 9). The last three dimensions in Table 9 are used in describing the respondents' views on collaboration (see Table 25) and the utility of the information they received about SS (see Table 26). Following each summarization, the findings are related to the literature relevant to each particular aspect of information about support services to look at the extent of agreement between the information gleaned from the SSISI and the information yielded by previous research.

Table 9

Classification of Responses on Items on the SSISI

Not Satisfied		Satisfied	
1	2 3	4 5	6 7
Very unclear	Somewhat clear	Moderately clear	Very clear
Totally Inadequate	Somewhat Inadequate	Moderately Adequate	Totally Adequate
Not at all Understandable	Somewhat Understandable	Moderately Understandable	Very Understandable
Not at all Useful	Somewhat Useful	Moderately Useful	Very Useful
Not at any time	Sometimes	Often	All of the time
Not at all	A little	A lot	A great deal
Not at all well	A little bit	Generally well	Very well

Cause of Hearing Loss Information

As shown below in Table 10, 49 parents (69.0%) indicated that they had received information about the causes of hearing loss in their children. Their level of satisfaction with the clarity, adequacy, understandability, and usefulness of this information was not that high. A quarter or less of the parents were very satisfied (7, 10, 8, 8). The majority (21, 25, 23, 25) indicated that they were only moderately satisfied while the remaining parents were either somewhat satisfied or not satisfied (21, 14, 18, 16). There seem to be issues of concern about the information provided to parents about the causes of their children's hearing loss.

Table 10
Satisfaction with Causes of Hearing Loss Information (n = 49)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	5	10	6	10	11	4	3
Adequacy	3	4	7	10	15	4	6
Understandability	4	5	9	11	12	4	4
Usefulness	5	4	7	11	14	5	3

Discussion

Although a majority of the parents indicated that they had received information about the cause of hearing loss, most of the respondents indicated that they were not satisfied with the clarity, adequacy, understandability and usefulness of the information. These findings are consistent with other research findings suggesting that parents of HIC are often not satisfied with the information they received about the etiology of their children's hearing loss (Brunger, Matthews, Smith, & Robin, 2001; Parker, Fortnum, Young, Davis, & Mueller, 2000).

Evidence indicates that in many cases of hearing loss, clinicians often face difficulties in accurately identifying the cause(s) (Ohlms, Chen, Stewart, & Franklin, 1999; Zakzouk & Al-Anazi, 2002). For instance, the cause of hearing loss could not be identified in 44 (41.1%) of the 107 HIC studied by Feinmesser, Tell, and Levi (1986). In a similar study, Parving (1984) reported that the cause of hearing loss remained unknown in 12 (38%) of the 32 HIC he studied. More recently, Walch, Anderhuber, Kole, and Berghold (2000) studied the causes of hearing loss in 102 HIC. In 47 children (46%) no cause of hearing loss could be determined. Kiesel-Himmel, Schroff, and Kruse (1997) studied the cause of hearing loss in 44 HIC. The cause of hearing loss was unknown in 19 (43%) of the children. Derekoy (2000) studied the cause of hearing loss in 130 HIC. The results indicated that there were 26.1% of unknown etiology. Of the 302 HIC studied by Zakzouk and Al-Anazi (2002), 45% had hearing loss of unknown etiology. Similarly, the causes of hearing loss could not be identified in 60 (52%) of the 114 HIC studied by Ohlms et. al. (1999).

The above studies indicate clearly that in a significant number of children with hearing loss the etiology remains uncertain. Consequently, the information about the cause of hearing loss given to parents may not be adequate, clear, understandable and useful. Continuing progress and research in the field of genetic disorders will, hopefully, diminish this number. Extensive interdisciplinary collaboration with audiologists, physicians, and related professionals is necessary for the etiological diagnosis of hearing impairment in childhood.

Coping Strategies Information

Overall, the majority of the parents indicated that they had not received information about strategies for coping. Only eighteen (25%) of the parents indicated that they had received information about coping strategies for dealing with negative reactions to the diagnosis of hearing loss in their children (see Table 11).

Table 11
Satisfaction with Coping Strategies Information (n = 18)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	-	2	3	5	6	1	1
Adequacy	1	2	5	6	2	1	1
Understandability	2	1	5	1	7	-	2
Usefulness	-	1	2	4	6	1	4

Only two, two, two, and five of these parents indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information provided for coping following the diagnosis of hearing loss in their children. Approximately half of the parents who had received such information (n = 11, 8, 8, 10) expressed moderate satisfaction. The remaining parents (5, 8, 8, 3) were either somewhat satisfied or not satisfied.

Discussion

Similar findings have been reported in other studies in which information about coping strategies was considered. Meadow-Orlans (1995) studied 20 parents and their strategies for coping with their HIC. The parents reported that lack of information about coping strategies was a major source of concern to them. Calderon and Greenberg (1999) studied the strategies for coping in 36 mothers with HIC. The results indicated that information about strategies for coping and available social supports or resources are essential for maternal adjustment to the diagnosis of hearing loss in their children. Taanila, Syrjälä, Kokkonen, and Järvelin (2002) examined factors affecting coping in 8 parents with physically and/or intellectually disabled children (aged 8 – 10 years). The results revealed that information about coping, acceptance, and social support were related to the successful coping strategies most frequently used. Half of the families who received information and support seemed to have found successful ways of coping, whereas the other half had major problems, indicative of lack of information and support.

It is possible that lack of information about strategies for coping might adversely affect parents with HIC. Consequently, the developmental needs of HIC may not be addressed in a timely manner resulting in delayed linguistic, cognitive, emotional and social development (Meadow-Orlans, Smith-Gray, & Dyssegaard, 1995; Oka & Ueda, 1998; Sloman, Springer, & Vachon, 1993). Evidence indicates that lack of information about strategies for coping can maintain denial in the parents of HIC and that they will continue to maintain the hope that a "cure" will be found (Schirmer, 2000). The dysfunctional communication in HIC is preserved by its circular relationship to unresolved grieving and denial (Sloman, et al. 1993). Sloman and co-workers noted that unresolved grieving over the child's hearing loss often makes it difficult for the parents to accept the importance of sign language to the language development of HIC. This increases the child's developmental problems and, ironically, creates more problems for the parents.

The findings of the present study are consistent with previous studies indicating that information about coping strategies is an area of concern to parents with HIC. The provision of information about coping strategies and about available support services can facilitate effective coping in parents with HIC. How this goal is to be achieved remains a challenge to professionals.

Counseling Information for Parents

Twenty-four (33.8%) of the parents indicated that they had received information about counseling services relevant for children with hearing loss (see Table 12). About half these parents found the information provided to be very clear (n = 12), understandable (11), and useful (13), while a quarter to a third of the parents (n = 6, 9, 9, 5) expressed moderate satisfaction with the clarity, adequacy, understanding and usefulness of the information. The remaining parents, approximately one-quarter (6, 8, 4, 6), were either somewhat satisfied or not satisfied.

Table 12
Satisfaction with Counseling Information (n = 24)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	1	3	2	-	6	9	3
Adequacy	1	2	5	2	7	6	1
Understandability	1	1	2	2	7	4	7
Usefulness	1	3	2	1	4	4	9

Discussion

Evidence indicates that information about counseling resources is crucially important to parents with HIC (Oka & Ueda, 1998; Pipp-Siegel, Sedey &

Yoshinaga-Itano, 2002). Information about counseling resources can assist parents with HIC in learning about the developmental needs of their HIC (Feher-Prout, 1996, Luterman, 1999; Shohet & Bent, 1998).

Although the importance of information about counseling resources to parents with HIC is well-documented, studies indicating that this information is made available to families with HIC are rare. The authors of the few studies that have been completed pointed out that counseling resources remain insufficiently stressed and addressed. For instance, Pipp-Siegel et al. (2002) studied counseling resources available to 184 parents with HIC. The results showed that the lack of information about counseling resources was identified as one predictor of parental distress. In a study of support services for parents with HIC in Denmark, similar results were reported (Mikkelsen, Nielsen, & Rasmussen 2001). These studies indicated that parents with HIC may not receive information about counseling resources. The findings of the present study indicate that only one-third of the participants received information about counseling resources. Information about counseling resources must be offered and should be offered to parents immediately after the diagnosis of hearing loss in their child(ren). Research focusing on strategies to enhance the provision of information about available counseling resources to families of newly diagnosed HIC is needed.

Counseling Information for Other Family Members

As shown below in Table 13, only 12 parents indicated that counseling information was made available to other family members. Of these 3, 2, 5, and 6 indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information about counseling resources provided to other members of their families. Five, 6, 3, and 2 other parents expressed moderate satisfaction. The remaining third of the parents (4, 4, 4, 4) were either somewhat satisfied or not satisfied. Taken together, these results suggest that two-thirds of the parents with HIC who received information about counseling resources for other family members found the information to be clear, adequate, understandable, and useful.

Table 13
Satisfaction with Counseling Information for Other Family Members (n = 12)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	2	2	-	2	3	2	1
Adequacy	2	2	-	3	3	1	1
Understandability	3	-	1	1	2	4	1
Usefulness	2	2	-	1	1	1	5

Discussion

The findings indicated that information about counseling resources for other family members (siblings, uncles, aunts and grandparents) of HIC was not provided to majority of the parents, and that the information provided was less than satisfactory. This is consistent with previous studies (e.g., Nybo, Scherman,

& Freeman,1998), which indicated that counseling needs of family members of children with special needs are often neglected.

Nonetheless, the importance of providing information about counseling resources and involving other family members in the development of HIC or other children with disabilities has been stressed in the field (e.g., Evans, Jones, & Mansell, 2001; Morton, 2001). Information about counseling is important for other family members because they may unnecessarily be expending a great deal of emotional energy learning how to cope with a child who is "different" in the family.

Research indicates that other family members can contribute immensely to the development of HIC when they receive counseling, and are involved in the care of the child. For instance, Nybo et al. (1998) studied the contributions of 21 grandparents to the development of their HI grandchildren. The results indicated that given adequate social support such as information about counseling resources and opportunity to be involved by the parents of HIC, grandparents were willing to provide diverse positive support to enhance the development of their HI grandchildren. Morton (2001) examined the support of other family members experienced by 10 parents of HIC. The results indicated that only a third of the participants reported positive support from other family members. The results suggest that counseling information might need to be provided to other family members so that they become more involved in supportive ways. Evans et al. (2001) examined the effectiveness of a program designed to support 28 children with learning disabilities and challenging behaviors. The results showed that the program, which incorporated counseling for other family members, increased the siblings' knowledge about learning disabilities, involvement with their disabled sibling at home, and their own self-esteem.

The findings of previous studies indicated that the provision of counseling information and the inclusion of other family members in intervention plans for HIC or other children with special needs can provide a solid emotional base for the children's growth and development. The results of the present study, however, indicate that parents with HIC may not receive such information. This seems to be an area of concern that service providers should give more emphasis.

Communication Needs Information

As shown in Table 14, 59 of the 71 parents (83.0%) indicated that they had received information about the communication needs of their children with hearing loss. A majority of the parents (29, 29, 36, 34) indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information they had received about their children's communication needs. One-third of these parents (24, 18, 13, 22) expressed moderate satisfaction, and the remaining parents (6, 12, 10, 3) were either somewhat satisfied or not satisfied. Taken together, the results suggest that the majority of parents appeared to be generally satisfied with the information they had received about their children's communication needs.

Table 14
Satisfaction with Communication Needs Information (n = 59)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	-	2	4	4	20	18	11
Adequacy	1	2	9	6	12	20	9
Understandability	1	2	7	2	11	17	19
Usefulness	-	-	3	5	17	12	22

Discussion

Evidence suggests that information about the communication needs of HIC is one prominent area of concern for parents (see, for example, Eleweke & Rodda, 2000; Marschark, Lang, & Albertini, 2002). Information about communication options for HIC is very important to parents for the development of HIC. If parents do not receive this information, they may not be in the position to make informed choices about the communication needs of their HIC (McKellin, 1995; Preisler, 1999; Siegel, 2000). If effective means of communication are lacking between parents and their HIC, the children's linguistic, social, emotional, and cognitive development will be needlessly delayed, often irreversibly (Lane et al., 1996; Vaccari & Marschark, 1997; White, 1999). Lack of information about communication options for HIC maintains ignorance about hearing loss and results in failure to provide early and effective communication experiences for HIC (Mukari et al. 1999; Siegel, 2000).

The results of the present study suggest that the majority of parents with HIC were at least moderately satisfied with the information they had received about their children's communication needs. This could be due to the service providers' effort to provide information relevant to the communication needs of HIC to their parents. Whatever the reason, it is a very welcome development. This information is important in facilitating the choice of communication methods parents select for their HIC.

Sign Language Course Information

Table 15
Satisfaction with Sign Language Course Information (n = 45)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	-	-	-	3	6	18	18
Adequacy	1	1	4	-	10	16	13
Understandability	-	2	1	1	8	13	20
Usefulness	1	1	2	4	4	3	30

Forty-five (63.4%) of the parents reported that they had received information about a course they could take to learn sign language to enhance communication with their HIC. Generally, they seemed to be satisfied with this information. The majority of the parents felt that the information was very clear (36), adequate (29), understandable (33), and useful (33). An addition of 9, 10, 9, 8 parents indicated that they were moderately satisfied with the clarity, adequacy, understanding and usefulness of the information.

Discussion

Research findings are consistent that sign language is an important option of communication (Rodda & Eleweke, 2000; Spencer & Erting, 2000; Stewart & Kluwin, 2001). Parents with HIC who receive information about courses in sign language may develop an interest in learning it to ensure effective communication with their HIC. Learning and using sign language with HIC by parents and other family members has a positive impact on the development of good language and communication skills in their children. For instance, Andrews and Zmijewski (1997) studied how the use of sign communication in the home can facilitate the development of literacy in HIC. Based on their study of 6 HIC and their families, they found that sign communication facilitated the development of literacy in HIC because sign language and finger spelling can be utilized by parents and other family members in reading story books to HIC, explaining prints, labeling, drawing with letters and words, writing lists and notes to family members, playing and experimenting with writing.

In contrast, Joseph and Alant (2000) found that if parents are not adequately informed and supported to learn sign language, they may not recognize its importance in the development of good communication skills in their HIC, and the parents' signing skills may be inadequate and awkward. They studied the signing skills of 45 parents of HIC. The results indicated that their signing ability was below that of their HIC, with sign vocabulary of 0-50 words for 85% of the participants. In a related work, Lederberg and Everhart (1998) studied communication between 20 HIC and their hearing mothers. The results showed that although the mothers used sign communication, they communicated with their HIC primarily through speech. This suggested that these mothers were probably not provided with information and support to acquire good sign communication skills. These findings indicated clearly that information about courses in sign communication should be provided to parents of HIC. Such information could enable them to: (1) take sign language classes, (2) acquire good signing skills, and (3) be able to enhance communication and interaction with their HIC.

Speech and Language Therapy Information

Forty-five of the parents (63.4%) indicated that they had received information about speech and language therapy services (see Table 16). However, as shown in Table 16, they were somewhat unevenly distributed with respect to their levels of satisfaction with the information provided.

Table 16
Satisfaction with Speech and Language Therapy Information (n = 45)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	2	3	9	7	10	7	7
Adequacy	5	3	8	6	13	4	6
Understandability	1	2	3	10	14	7	8
Usefulness	6	5	5	10	6	5	8

Slightly less than one third of the parents (14, 10, 15, 13) indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information they had received about speech and language therapy services. Seventeen, nineteen, twenty-four, and sixteen of the parents expressed moderate satisfaction with the clarity, adequacy, understanding and usefulness of the information they had received about speech and language therapy services. The remaining parents (14, 16, 6, 16) were either somewhat satisfied or not satisfied.

Discussion

Previous studies of information about speech and language therapy services have indicated that providing adequate information to parents about these services increases their enthusiasm for participation in programs for HIC (Glogowska & Campbell, 2000; Glogowska, Campbell, Peters, Roulstone & Enderby, 2001). These authors suggested that the key to successful provision of speech and language therapy services to HIC is the involvement of parents. Evidence suggests that when information is provided to parents after the diagnosis of hearing loss, and parents are encouraged and supported to be involved in the speech and language therapy services provided to their HIC, positive outcomes are obtained in language development for these children. For instance, Glogowska and Campbell (2000) studied the views and impact of the information about speech and language therapy services provided to 16 parents of pre-school-aged HIC. The results indicated that because of the information they received, these parents viewed their involvement as crucially important to the success of the intervention program. Similarly, Moeller (2000) studied early intervention and language development programs provided to 112 HIC who were 5 years of age. The results showed that the provision of adequate information about these services enhanced parental involvement and facilitated the initiation of speech and language therapy services after the diagnosis of hearing loss. It is evident from these studies that if treatment acceptability and effectiveness in the provision of speech and language therapy services to HIC are to be achieved, it is imperative that parents are given information about these services and supported to be involved. It is matter of concern that 46.6% of the parents indicated that they had not received this information. Research into strategies that could ensure that all parents of HIC receive this information is needed.

Hearing Aid Information

Table 17
Satisfaction with Hearing Aid Information (n = 65)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	-	2	6	4	12	23	18
Adequacy	1	3	2	3	16	19	21
Understandability	-	2	2	6	15	21	19
Usefulness	1	1	3	6	14	19	21

Of the 71 parents, 65 (91.5%) indicated that they had received information about hearing aids as shown above in Table 17. There seems to be general satisfaction with the information the parents received about hearing aids.

Approximately two-thirds of the parents (41, 40, 40, 40) indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information they had received about hearing aids. Only eight, six, four, and five of the parents were either somewhat satisfied or not satisfied.

Discussion

Information about hearing aids is important to families with HIC. Hearing aids are important for HIC because they can facilitate the development of verbal communication in some HIC. Information about these devices enables parents and other family members to be able to monitor the hearing aids that HIC use (Diefendorf & Arthur, 1987; Hoover, 2002; Mukari, et al. 1999). In particular, hearing aid fitting for HIC under the age of 1 year provides many challenges not only to audiologists but to the parents as well (Winter & Eisenberg, 1999). This is because the development of modern hearing aids has been so great that they now represent the cutting edge of micro-electronics. The digital signal processing and computer-aided programming of these devices have been greatly enhanced. These developments enable improved customization of individual hearing aids (Arlinger, 1999). Information that will facilitate good understand of how these devices function is, therefore, very important for parents with HIC.

Evidence indicates that parental support is essential for HIC to accept wearing hearing aids in the first place. Kiesel-Himmel and Kruse (2000) examined the acceptance of wearing a hearing aid by 116 HIC. The parents of these HIC rated the children's acceptance and consistent wearing of the hearing aids as follows: “excellent” or “good” (58.6%), “average” (18.1%), “bad” to “miserable” or even “not at all” (23.3%) (pp.309-313). It is suggested that those HIC who received strong support and encouragement from their parents accepted and used their hearing aids consistently.

Evidence indicates that consistent and appropriate use of hearing aids can facilitate the development of verbal communication skills in HIC. For instance, Rhoades and Chisolm (2002) examined language development and growth in 40 HIC who were using hearing aids over a period of four years. The results indicated that the receptive and expressive language skills of the HIC were similar to those of their normally hearing peers.

In a related study, Moeller (2000) examined vocabulary skills in 112 HIC who were 5 years of age and who were provided a variety of early intervention services, including the use of hearing aids after the diagnosis of hearing loss. The results revealed that HIC who were identified early and promptly provided with amplification and other early intervention services demonstrated vocabulary and reasoning skills approximating those of their normally hearing peers. Further, Moeller (2000) found that higher levels of family involvement correlated with positive language outcomes, and conversely, limited family involvement was associated with significant language delays at 5 years of age, especially when diagnosis and initiation of intervention was late.

It is encouraging that the majority of parents in this study indicated that they received clear, adequate, understandable, and useful information about hearing aids. This implies that if their HIC were fitted with hearing aids, they have the information that could make it possible that these devices produce positive outcomes for their children.

Cochlear Implant Information

Thirty-three of the 71 parents (46.5%) indicated that they had received information about cochlear implant devices. Their level of satisfaction with the clarity, adequacy, understandability, and usefulness of the information provided to them about cochlear implants was not that high (see Table 18).

Table 18
Satisfaction with Cochlear Implant Information (n = 33)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	5	6	5	5	6	4	2
Adequacy	1	5	5	10	6	4	2
Understandability	2	5	4	10	3	7	2
Usefulness	7	7	2	9	2	3	3

One-fifth of the parents (6, 6, 9, 6) indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information they had received about cochlear implants. Approximately one-third to one-half of the parents (11, 16, 13, 11) expressed moderate satisfaction with the clarity, adequacy, understanding and usefulness respectively of the information they had received, while one-half to a third (16, 11, 11, 16) were either somewhat satisfied or not satisfied. Clearly, the clarity, adequacy, understandability and usefulness of the information provided to parents with HIC about cochlear implants seems to be an area of concern.

Discussion

While a majority of the parents indicated that they had not received information about cochlear implants, a little over half of those who had received this information were at least moderately satisfied with the clarity, adequacy, understanding, and usefulness of the information. The findings of previous studies about the information provided to families with HIC about cochlear implants since their introduction about 10 years ago as an alternative to conventional hearing aids are somewhat contradictory (Brinton, 2001; Lane & Grodin, 1997; Steinberg, Brainsky, Bain, Montoya, Indebaum & Postic, 2000). Besides conflicting accounts of the efficacy of cochlear implantation for HIC (Hammes, Novak, Rotx, Willis, Edmondson & Thomas, 2002), the information provided to parents about these devices may be confusing because the procedure is beset by ethical dilemmas raised by a linguistic and cultural minority called the Deaf World (Lane & Bahan, 1998; Lane & Grodin, 1997). Organizations of culturally Deaf people in Canada, the United States, the United Kingdom, and in other countries, as well as the World Federation of the Deaf have strongly criticized the practice of cochlear implant surgery in HIC due to ethical concerns (Lane & Bahan, 1998). According to Lane and Bahan (1998, pp.297-313) The Deaf World is opposed to the procedure because (1) the value of the implantation for enhancing the acquisition of spoken language by HIC remains unproven, (2) HIC should be exposed to the use of sign languages of the world, which are full-fledged natural languages, and (3) the procedure could result in the annihilation of the Deaf World.

Further, cochlear implantation is an expensive surgery costing between $12, 000 to $18,000 (US). This cost is often not covered by public funding and can contribute to financial stress in families with HIC (O'Neill, Archbold, Donoghue, McAlister, & Nikolopoulos, 2001). Nonetheless, several recent studies indicated that with the provision of adequate information to parents and with their support, cochlear implants can provide some HIC access to quality sound enabling them to acquire speech and verbal language at a rate similar to normally hearing children (Geers, Brenner, Nicholas, Uchanski, Tye-Murray, & Tobey, 2002; Hammes et al., 2002; Kirk, Miyamoto, Lento, Ying, O'Neill, & Fears, 2002; Robbins, Bollard, Green, 1999).

Thus, despite the controversies surrounding it, cochlear implantation can be of immense benefit for some HIC. The challenge for service providers is to provide clear, adequate, understandable, and useful information to parents with HIC, including the limitations of cochlear implants so that parents will be in the position to make informed choices.

Assistive Listening Device Information

As shown in Table 19, 39 of the parents (54.9%) indicated that they had received information about assistive listening devices, such as flashing doorbells and telephone flashers. There seems to be a high level of satisfaction with the clarity, adequacy, understandability, and usefulness of the information about assistive listening devices these parents had received. The majority of the 39 parents (34, 23, 33, 31) indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information they had received about assistive listening devices. Only two, two, one, and two of the parents were either somewhat satisfied or not satisfied with the clarity, adequacy, understandability, and usefulness of the information.

Table 19
Satisfaction with Assistive Listening Device Information (n = 39)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	1	-	1	1	2	23	11
Adequacy	1	1	-	2	12	16	7
Understandability	1	-	-	1	4	17	16
Usefulness	1	-	1	2	4	7	24

Discussion

Although research into families' perceptions of information about assistive listening devices is scarce, evidence indicates that information about these devices is essential to families with HIC because these devices can greatly enhance communication for individuals with hearing loss and members of their family

(Tomita, Mann, & Welch, 2001). Assistive listening devices such as alerting devices, devices that amplify television, telephone, hearing aid, teletypewriters, and other various signaling devices play an ever increasing role in the lives of HIC and other individuals with hearing losses (Baumfield, Hickson, & McPherson, 1993; Loovis, Schall, & Teter, 1997; Schirmer, 2000). These devices serve to alert a hearing-impaired person to changes in the environment that cannot be perceived auditorially, maximizing the person's hearing efficiency, enhancing communication, and fostering independent living (Pehringer, 1989).

Information about these devices is important to parents with HIC because these parents play an integral role in the evaluation, selection, and management of assistive listening devices. Moffitt (1999) observed that parents need information in order to select appropriate assistive listening devices for their HIC. In order to obtain maximum benefit from whatever assistive listening device is being used, parents must have adequate information so that they can teach their children how to learn to listen to and make use of the information available through that device. Specific instruction or training accelerates this learning and enables the children to develop strategies to facilitate the comprehension of important environmental signals (Moog, Biedenstein, Davidson, & Brenner, 1996).

Continuing progress in technology is expected to give greater access to auditory signals in all types of listening situations to individuals with hearing loss. Consequently parents with HIC must be provided adequate information about these devices so that they can participate in the selection, use, and management of assistive listening devices used by their HIC.

Education Options Information

Table 20
Satisfaction with Education Options Information (n = 59)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	2	3	2	2	5	20	25
Adequacy	2	7	3	4	6	28	9
Understandability	-	2	6	1	7	22	21
Usefulness	2	4	2	8	1	14	28

Fifty-nine (83.1%) of the 71 parents indicated that they had received information about educational options for their children with hearing loss (see Table 20). The majority of these parents (45, 37, 43, 42) indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information they had received. Approximately one out of six of the parents either expressed moderate satisfaction (7, 10, 8, 9) with the clarity, adequacy, understanding and usefulness of the information they had received or were either somewhat satisfied or not satisfied (7, 12, 8, 8) with the clarity, adequacy, understanding and usefulness of the information. Generally, there seems to be a high level of satisfaction with the information about education options among a majority of the parents.

Discussion

Evidence indicates that when provided adequate information about education options, parents with HIC are not only able to make informed educational choices, they also support the educational programs for their HIC (Calderon, 2000; Eleweke & Rodda, 2000; Tuscano, McKee, & Lepoutre, 2002). Evidence is consistent that information about education options for HIC is essential for parents to actively participate in the educational programs of their children. Indeed, parental involvement in the education of HIC has long been recognized to benefit the children, parents, teachers, and the schools in general (Gabriel & Getch; 2001; Good, 2001). Calderon (2000) examined the impact of information about education options on parental involvement in educational programs of 28 HIC. The results revealed that parents who received information about educational options were committed to their children's educational success. He found that parental involvement in HIC's educational programs is a positive predictor of HIC's language, early literacy, social, and emotional development. Kluwin and Corbett (1998) studied the extent of involvement of 105 parents in the educational programs of their HIC. The results showed strong involvement by those parents who received substantial information about their children's educational options.

One might assume that if parents are very satisfied with the information given about education options as this study shows, they will be in the position to make informed choices and be involved in the educational programs of their children. Service providers should ensure that parents with HIC are provided information about the education options that can be available for their children.

Funding Resources Information

Less than half, 29 (40.8%), of the 71 parents indicated that they had received information about available funding resources to assist in meeting the costs of providing services to their children with hearing loss (see Table 21).

Table 21
Satisfaction with Funding Resources Information (n = 29)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	3	4	1	3	8	4	6
Adequacy	5	3	2	6	5	4	4
Understandability	2	1	1	4	8	3	10
Usefulness	7	3	3	1	6	4	5

Approximately one-third of these parents indicated that they were very satisfied (10, 8, 13, 9), one-third moderately satisfied, (11, 11, 12, 7), and one-third not satisfied (8, 10, 4, 13) with the clarity, adequacy, understanding, and usefulness of the information they had received about available funding resources. Taken together, the parents' views were mixed about the levels of satisfaction with the information about funding resources provided to them.

Discussion

Previous research indicates that information about funding resources is essential to families with HIC or other children with special needs because devices such as hearing aids, cochlear implants, and special education programs can be too expensive for families (Leake, Thompson, Simms, Bailey, Stocks, & Murphy, 2000). High costs have been identified as the prominent barrier to the use of amplification and assistive listening devices by many individuals with hearing loss (Kawachi & Kennedy, 1999; Levitt & Bakke, 1995). For instance, 94 (4.8%) of the 1,950 patients studied by Hubbell, Waitzkin, Rucker, Akin, and Heidi (1989) were unable to afford the purchase of hearing aids recommended for them. More recently, Leake et al. (2000) examined families with 50 HIC to ascertain whether the families received information about funding resources, and whether their financial situation had a negative effect on the acquisition of hearing aids and assistive listening devices. The results indicated that two-thirds of the participants were at or below the poverty level and therefore could not afford the cost of these devices on their own. Leake and co-workers (2000) also found that there were sources of funding in the community for the purchase of these devices but that many parents with HIC were unaware of these. The results of the present study also show that the majority of parents, 42 (59.2%), indicated that they had not received such information. Information about available funding sources could be an area of concern or need for families with HIC. Consequently, there is need for service providers to ensure that families with HIC are given information about available external sources of funding for the devices and services that are critically important for the successful development of their children.

Deaf Culture and Community Information

Table 22
Satisfaction with Deaf Culture and Community Information (n = 28)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	-	3	-	-	5	10	10
Adequacy	-	2	2	1	5	11	7
Understandability	-	1	-	1	7	8	11
Usefulness	-	1	1	-	1	6	19

As Table 22 shows, only 28 (39.4%) of the parents indicated that they received information about Deaf culture and community. There seems to be a generally high level of satisfaction with the information these parents received about Deaf culture and community. For example, a majority of the parents (20, 18, 19, 25) indicated that they were very satisfied with the clarity, adequacy, understanding and usefulness of the information they had received. Of the remaining parents, 18% (5, 6, 8, 1) expressed moderate satisfaction with the clarity, adequacy, understanding and usefulness of the information they had received, while 9% (3, 4, 1, 2) of them were either somewhat satisfied or not satisfied.

Discussion

It is a matter of concern that the majority of the 71 parents, 43 (60.6%), indicated that they had not received information about Deaf culture and community. Bat-Chava, (2000), Lane et al. (1996), and Moores (2001) indicated that families with HIC might not be aware of the Deaf culture and community.

Lane et al. (1996) and Moores (2001) suggested that hearing service providers who hold the view that deafness is a disability shape the initial views of the 92% of the hearing parents of HIC who have no knowledge of deafness. Many of these professionals hold unfavorable views about the Deaf community and culture. Consequently, they may not provide information about the Deaf culture and community to parents with HIC. Unless they are adequately informed, these parents may not view the Deaf community positively. In contrast, Bat-Chava (2000) reported that most parents of HIC who are adequately informed or who are Deaf themselves are positive about Deaf culture and community.

Evidence indicates that information about the Deaf community is essential to families with HIC. This is because some services and activities provided by the Deaf community can assist parents in the development of language, communication and literacy skills in their HIC (Grushkin, 1998). Most of the Deaf community members are Deaf adults. These people are cultural role models and have a wealth of educational, social, communication and language resources that could immensely benefit HIC and their families.

Evidence indicates that hearing parents with HIC who had received information about the Deaf community often found services provided by the Deaf community to be very useful in the development of their children. For instance, Takala, Kuusela, and Takala (2001) studied 81 parents of HIC to ascertain whether they had received information about the Deaf community. The results showed that the parents who indicated that they had received information about the Deaf community were generally satisfied with contact they had with the Deaf community. Information and contact with the Deaf community afforded them the opportunity to acquire sign language skills to enhance communication with their HIC. Their communicative competence and social adjustment skills were improved by contacts with the deaf community. The Deaf community has rich resources that families with HIC can find invaluable in the care and development of their children. Considering the benefits that families with HIC can derive from the Deaf community, the results of the present study suggest that families with HIC need to be provided with appropriate information that will encourage their association with members of the Deaf community.

Informal Support Network

Only 13 (18.3%) of the 71 parents indicated that they had received information about informal support networks, such as parent support groups comprised of parents of children with hearing loss (see Table 23).

Table 23
Satisfaction with Informal Support Network Information (n = 13).

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	-	1	2	4	1	4	1
Adequacy	4	2	1	5	-	1	-
Understandability	-	-	3	3	-	5	2
Usefulness	-	1	-	5	1	3	3

Five, seven, and six of the parents expressed a high level of satisfaction with the clarity, understanding, and usefulness of the information they had received about informal support networks. One parent was very satisfied with the adequacy of the information. Five, five, three and six of the parents indicated moderate satisfaction with the clarity, adequacy, understandability, and usefulness of the information. The remaining parents (3, 7, 3, 1) were either somewhat satisfied or not satisfied. It is a matter of concern that 58 (81.7%) of the parents indicated that they had not received this information.

Discussion

Considering evidence that informal support networks can be of immense benefit to families with HIC or other children with disabilities (Ehlers-Flint, 2002; Llewellyn & McConnell, 2002; White, 1999), it is a matter of concern that 81.7% of the respondents indicated that they had not received information about these networks. The finding of the present study is consistent with the findings of some previous studies. For instance, only 9.5% (n = 30) of the 317 parents of HIC studied by Hintermair (2000) indicated that they received some information about informal support networks and were involved in these social networks. He found that information about informal support networks provided opportunities for parents with newly diagnosed HIC to meet with parents of older HIC. The former group could obtain first-hand information about raising HIC from the latter group. Further, Hintermair found that parents with HIC who frequently met with other parents demonstrated warm, accepting, and trusting relationships with their HIC.

Information about informal support networks that function without conflict and that provide emotional support can make a tremendous difference when one is trying to cope with difficulties arising from having a child with a hearing loss. Information about informal social support networks is essential because these networks can be vital contributors to the development of personal identity patterns, even under extraordinarily difficult conditions (Bodner-Johnson, 2001). These informal networks are important in maintaining social identity in times of crisis. This is because these social networks are welcoming and afford people the opportunity to share their life experiences relating to critical life events such as the diagnosis of hearing loss in a child. Participants in social networks learn how others have coped successfully and apply this knowledge to their own life situations (Broome, Simpson, & Joe, 2002; Hintermair, 2000). The results of the previous studies indicate that it is very important that service providers ensure that information about informal social support networks be provided to parents with newly diagnosed HIC.

Formal Support Resources Information

Table 24
Satisfaction with Formal Support Resources Information (n = 26)

Domain	Frequencies						
	1	2	3	4	5	6	7
Clarity	-	1	1	2	4	9	9
Adequacy	-	1	-	3	3	12	7
Understandability	-	1	-	3	2	11	9
Usefulness	1	-	3	2	2	9	9

As shown above in Table 24, 26 (36.6%) of the parents indicated that they had received information about formal support resources. About two-thirds of these parents (18, 19, 20, 18) expressed a high level of satisfaction with the clarity, adequacy, understanding and usefulness of the information they had received about formal support networks. Slightly less than one-quarter of the parents (n = 6, 6, 5, 4) expressed moderate satisfaction. Only a few (2, 1, 1, 4) were either somewhat satisfied or not satisfied. As was the case with the information about informal support networks, most of the parents were at least moderately satisfied with the information, but a majority of parents, 45 (63%) indicated that they had not received information about formal support networks.

Discussion

A majority of the 71 parents 45 (63%) indicated that they had not received information about available formal support resources. Likewise, Benson, Sharma, and Roehlkepartain (1994) found that a majority of 2000 adoptive families they studied were unaware of the formal support they could receive from professionals. Evidence is consistent that parents with HIC or other children with special needs may not have received this information (Krause, 1990; Llácer, Zunzunegui, Gutierrez-Cuadra, Beland, & Zarit, 2002). Guidry, Aday, Zhang, and Winn (1997) observed that often professionals do not provide information regarding formal support groups to families at the time of diagnosis.

Nonetheless, information about formal support networks, as well as the importance of involvement with these networks is helpful to families with HIC.

Formal support networks should be offered as part of the formal program of care provided to families with HIC. Formal support networks involve the provision of helpful information and resources to families with HIC by service providers. Strategies such as group discussion, focus groups, mentoring of parents, and informal question-and-answer sessions can be effective in helping and supporting parents of HIC in the acquisition of knowledge and skills concerning the development of their children (Poyadue, 1993).

Another means of providing formal support to families with HIC is by organizing frequent formal informational meetings, such as panels of experienced parents of HIC, Deaf adults, and various professionals (Bodner-Johnson, 2001). Such sessions can focus on topics identified as being of interest to the parents of HIC. Whatever the format, allowing sufficient time for discussion is critical for the session to be informative and useful to families. Formal support activities as described above are helpful in educating parents about the developmental needs of their HIC.

The results of the present study show that many of the participating parents did not get information about formal support networks. The challenge of service providers is to explore strategies to ensure that parents are informed of the availability of such networks and to encourage them to participate in them. These networks should be part of the parents' total treatment experience and must be acknowledged by healthcare professionals.

Views on Collaboration

All 71 parents indicated that they had received different services from different professionals in the field of hearing loss. Shown in Table 25 are the parents' perceptions of the quality of their collaborative experiences with the professionals. They reported that the professionals were willing to listen, caring and considerate, sensitive to parents' concerns, involved parents in making decisions, encouraged feedback from the parents, and considered such feedback in making decisions. Approximately half or more of the parents (35, 41, 39, 37, 24, 39) indicated that these six dimensions of collaboration with professionals occurred all of the time.

Table 25
Views on Collaboration (n = 71)

Domain	Frequencies							
Not at any time	1	2	3	4	5	6	7	All of the time
Willingness to Listen	-	2	4	17	13	21	14	
Caring and Considerate	-	4	7	6	13	18	23	
Sensitivity to Parents' concerns	1	3	5	8	15	26	13	
Involvement in Decision-making	1	3	7	7	16	20	17	
Feedback Encouraged	3	4	7	12	21	15	9	
Feedback considered	2	3	8	7	12	19	20	

Approximately one-third of the parents (n = 30, 19, 23, 23, 33, 19) indicated that these same aspects occurred often, while about one-fifth or less (6, 11, 9, 11, 14, 13) indicated that they experienced these dimensions of collaboration sometimes. One parent did not at any time experience professionals' sensitivity to the parent's concerns, another parent was not at any time involved in decision making, three parents were not at any time encouraged to provide feedback, and two parents indicated that the feedback they provided was not at any time taken into consideration in making decisions.

Discussion

A majority of the parents indicated that the professionals were willing to listen, caring and considerate, sensitive to parents' concerns, involved parents in making decisions, encouraged feedback from the parents, and considered such feedback in making decisions all of the time. These parents were satisfied with their collaborative experiences with the professionals. Evidence indicates that frequent and positive collaborative encounters between parents and professionals in the planning and implementation of program of care for children with disabilities can be satisfying to parents and is being increasing emphasized in the provision of support services (Harley & Tice 2002; Parrette, Brotherson, & Blake, 2000; Schnieders & Tafoya, 1998; Shankar, 2002). Collaboration between professionals and parents assists parents in (1) acquiring the resources to successfully deal with their grieving at the diagnosis of hearing loss, (2) acquiring education regarding the concept of communication options for HIC and educational resources, and (3) finding needed services, agencies and resources (Cherow, et al. 1999, pp. 153 –162).

Evidence is consistent that effective collaboration between professionals and parents leads to achieving positive outcomes in the care of children with special needs or disabilities. For instance, Brown (2001) studied the views of 18 parents of children with disabilities regarding the factors that contributed to the effectiveness of early intervention programs for their children. The results revealed that effective collaboration between professionals and parents is one of the predictors of the effectiveness of the early intervention programs. Hanson, Beckman, Horn, Marquart, Sandall, Greig, and Brennan (2000) examined the choices, decisions and experiences of 22 families of children with developmental challenges regarding the children's transition from infant-toddler services to preschool services. The results indicated that without information exchange and communication between professionals and parents, the shift in service delivery from infant-toddler to preschool was often problematic. The findings revealed that without adequate information families had limited choices about preschool programs. This suggested the absence of effective collaboration between service providers and the parents. Norton (1998) examined 22 families to identify the factors influencing child mental health treatment. Parent-professional collaboration was found to have a significant effect on parents' sense of efficacy and treatment outcomes. A survey of 445 caregivers of children with severe emotional disorders (DeChillo, et al. 1995) indicated that supportive relationships between caregivers and professionals, involvement of caregivers in planning and implementing treatments, and forthright information exchange are the predictors of effective collaboration and facilitators of successful treatment. These findings indicate that increased collaboration leads to increased efficacy of rehabilitation services. Clearly, collaboration is essential in order to provide appropriate services to HIC and their families. Service providers appear to have the education and expertise that will enable them to forge links with parents in the care of HIC.

Usefulness and Impact

The parents expressed varying views about the usefulness and impact of the information and support services they received (see Table 26). Twenty-one (34.4%) of the parents indicated they were able to obtain the services their children with hearing loss needed all of the time. Slightly less than half of the parents (27) indicated that they were often able to obtain the needed services, 11 indicated that they were sometimes able to obtain the services, and 2 indicated that they did not at any time obtain the needed services.

Table 26
Utility of Information Received

Domain	Frequencies							
Not at any time	1	2	3	4	5	6	7	All of the time
Extent needed services obtained	2	6	5	10	17	13	8	(n=61)
Not at all								A great deal
Extent information and SS received improved family life	-	3	3	7	14	19	20	(n=61)
Not at all well								Very well..
Extent information and SS received improved ability to care for HIC	-	3	3	5	21	16	18	(n=62)

Of the 61 parents who rated how their family life was improved as a result of the information and services they had received, 39 (63.9%) indicated that their family life was improved a great deal, 21 indicated that their family life was improved a lot, and 6 indicated that there was a little improvement in their family life.

Sixty-two of the 71 parents rated how the information and services they had received increased their ability to care for their children with hearing loss. The majority of these parents, 34 (54.8%) indicated that the their ability to care for their HIC improved very well, 26 indicated that their ability improved generally well, and 6 indicated that their ability improved a little bit. Taken together, it seems to be the case that the information the parents received enabled the majority of them to obtain the essential services their HIC required, improved their family lives, and increased their ability to care for their HIC.

Discussion

The results showed that a majority of the parents indicated that the information they had received helped them to obtain the services their HIC needed, improved their family lives, and increased their ability to care for their HIC. Evidence is very consistent that parents who are provided with the relevant information about their children's developmental needs tend to make good use of the information to obtain the services their children require (Perrino, Coatworth, Briones, Pantin, & Szapocznik, 2001; Sussell, Korinek & Bullis, 1996). Meadow-Orlans, Mertens, Sass-Lehrer, and Scott-Olson (1997) examined the perceptions of 404 parents of HIC concerning the information about support services provided to them. The results indicated that those parents who had received information gave highly favorable evaluations of the support services and intervention programs they had received.

Meyers and Bartee (1992) examined factors influencing improvements in signing skills of 106 hearing families with HIC. Their results suggested that adequate information about the importance of sign language to HIC and support to learn it could motivate parents, siblings, and other family members to not only acquire signing skills, but also to work on improving them. MacTurk, Meadow-Orlans, Koester, and Spencer (1993) examined factors influencing early cognitive, social and language development in HIC. Twenty mothers with HIC and 20 mothers with normally hearing children participated in the study. The findings showed that information and support services provided to the mothers with HIC were found to have positively influenced the cognitive, social and language development of the HIC. Those findings indicated clearly that given the relevant information, parents of HIC will find it useful obtaining services essential to the development of their children.

Summary

The data collected with the SSISI provided insights into the perceptions of the SS information received by families with HIC. The data illuminated the extent the participants considered that the information they received about SS was clear, adequate, understandable, and useful. Taken together, the findings indicated that some families with HIC may not often receive clear, adequate, understandable, and useful information about SS. Consequently, some families may be unable to obtain the essential SS that would have otherwise assisted them in the care of their HIC. In contrast, those families who received appropriate information about the developmental needs of their HIC may be in a better position to obtaining the services essential for their children's development.

Further, the participants were very consistent in their responses. When the results of the present study are placed in the context of reported research on the information about SS for HIC and their immediate and extended families, there is much agreement. This provides additional evidence that the SSISI can provide information that can be validly and reliably interpreted. In addition, it suggests that the instrument could also yield information that could be used by service providers to improve the dissemination of information about services to families with HIC.

CHAPTER 6

SUMMARY AND CONCLUSION

The purpose of the present study was to develop an instrument that could be used to examine how parents with HIC perceived the clarity, adequacy, understandability, and usefulness of the information they received about support services available to meet the developmental needs of their hearing-impaired children. Obtaining information about the developmental needs of HIC and support services available in the community remains a major challenge for many families with HIC. This is because 92% of the parents of HIC are normal hearing people with no previous experience of deafness in the family. Information about support services is essential to assist these families in meeting the developmental needs of their children.

Clearly, focusing on the family and their perceptions of the information they had received about support services is justified. Support services are critically important to families with HIC. Families should not be require to spend time and effort to find them. The availability of relevant information about support services is of immense assistance to families with HIC. These services offer flexible programs, focus on the entire family, change as family needs change, encourage families to utilize various sources of support in the community, as well as provide convenient access to coordinated services and resources (Pendergast, et al., 2002; Seltzer & Essex, 1998). Families would benefit more by receiving relevant information about SS from coordinated teams of professionals (Pendergast, et al. 2002; Robinshaw & Evans, 2001).

It remains the case, however, that families with HIC may be frustrated by the lack of relevant information about support services. The literature indicates clearly that lack of information about support services remains a major need of families with HIC (see for example, Lane, et al. 1996). Lane et al. observed that ensuring that families with HIC are provided with clear and unbiased information about the developmental needs of these children and the support services available in the communities remains a challenge to professionals and service providers. It remains the case that due to lack of information about support services, there can be lengthy delays prior to the initiation of intervention services after hearing loss has been diagnosed (Yoshinaga-Itano, 2000). Abundant evidence confirms the positive effects of timely initiation of intervention programs immediately following the diagnosis of hearing loss on linguistic, cognitive, emotional and social, and educational achievement of HIC (Marschark, 1998; Robinshaw, 1995; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). It can be assumed that given adequate information about support services, families with HIC (1) have the flexibility to respond in a positive and beneficial way, and (2) may be able to the obtain the services their children require.

In view of the foregoing discussion, this study was taken up to develop an instrument that could be used to examine parental perception of information about support services provided for HIC and their families. Although the importance of information about support services for HIC and their families is well documented, research into families' perceptions of the information on these support services for HIC is lacking. This study was an attempt to fill that gap. As a result, this study was concerned with systematically developing an instrument that could be of value in gathering evidence concerning families' perceptions of information about these essential support services.

Summary of Procedures

There was no instrument readily available that could be used to gather evidence concerning the perceptions of families with HIC of the information they had received about support services. Consequently, the major aim of the present study was to develop an instrument that could be useful in gathering such evidence. The systematic approach to the development of a measuring instrument discussed by Crocker and Algina (1986) was followed to develop the instrument. This approach involved: (1) determining the purposes for which the assessment from the instrument will be used, (2) identifying and describing the outcomes indicative of good SS information provision for families of HIC, (3) construction of an initial pool of items and methods of scoring, (4) review of the items in the instrument by a panel of experienced SS professionals and families with children with hearing loss, (5) conducting a primary pilot trial on a sample of families of HIC and modifying the instrument as necessary, (6) field testing the instrument on a larger sample of families of HIC, and (7) analyzing the data. Activities related to the first three steps were described in Chapter Three. Activities and results from Steps Four and Five were discussed in Chapter Four. Activities and the results related to steps Six and Seven were discussed in Chapter Five.

Step 1 to Step 3

The primary purpose of the assessment scores derived from the instrument was two-fold. First, the scores would produce information for SS professionals about the perceptions of families with HIC of the SS information they have received. Second, the results would have implications for intervention purposes. A family's responses could be used as a basis for discussion of their opinions about the SS information provided to them, of why certain SS were inaccessible, or why some services might be available but were not used as sources of support and resources for meeting needs.

The instrument was developed by first identifying the essential outcomes of provision of information about effective SS to families with HIC. The extensive review of the literature on SS (Chapter Two) covered journal articles, books, book chapters, and dissertations by scholars and researchers. Information about support services for families of children with and without special needs in general and those with HIC in particular were considered. The review generated five major areas that should be the focus of providing information about SS, namely, (1) strategies for dealing with reactions to the diagnosis of hearing loss, (2) developmental needs, counseling and guidance, (3) opportunity for participation in early intervention programs, (4) fostering the educational development of HIC, and (5) empowerment of families through collaboration with SS professionals. Using the findings of this review, 32 items were generated and constituted the first draft of the Support Service Information Satisfaction Scale Inventory (SSISI, see Appendix B).

Step 4: Panel Review

A panel of experts in deafness and families of children with hearing loss reviewed the first draft of the Support Service Information Satisfaction Inventory (SSISI). The panel comprised seven professionals who were experienced in the provision of services to families of children with hearing losses and three parents (mothers) of children with hearing loss. The panel assessed the items of the SSISI for content related validity evidence (see Chapter 4). The panelists agreed with the sequencing of the new instrument and that the items were clearly written and unambiguous. The panelists indicated that generally the items on the instrument were relevant with respect to information concerning support services for families with HIC. Similarly, they were all in agreement that the essential domains and outcomes of support services for families of children with hearing losses were adequately represented by the items. However, 4 panelists suggested that there were 3 additional aspects of information about SS for families with HIC that needed to be considered. They recommended the following three aspects:

* Funding resources for families

* Informal - peer (families of deaf children) support networks

* Cochlear implants

The recommendations were accepted and incorporated into the instrument. The modified form became the final instrument for field-testing. Prior to the field-testing, the modified instrument was pilot tested with 13 families of HIC whose children were receiving services from two educational institutions for HIC. The pilot test was to assist in further refining the items in the SSISI. The parents did not recommend any changes to the instrument. However, two parents made comments about the need to include open-ended questions. Open-ended questions were not included in the SSISI because it was expected that after it had been validated service providers would discuss a family's responses to the instrument with the family and obtain more details concerning any aspect of support service needs of the family.

Step 5: Field Test

Following the completion of the panel review and the pilot test, the instrument was field tested on a sample of 71 families with HIC in Edmonton, Calgary, Red Deer, and Leduc in Alberta, Canada; and Muncie, Fort Wayne, Hew Haven and Indianapolis in Indiana, the United States. A letter was sent to directors of three educational institutions, seven itinerant teachers of the deaf, five educational consultants and four agencies providing services to families with HIC in these locations (Appendix K). The letter explained the purpose of the study and requested their permission and assistance in administering the instrument to families with HIC, preschool to junior high school in age. One educational institution, one support service provision agency, five itinerant teachers of the deaf and two educational consultants agreed to assist with transmitting the instrument to families with HIC. Packets containing a cover letter (Appendix L), the Informed Consent Form (Appendix D-iii), the instrument (Appendix J), and postage-paid envelopes were sent to families with HIC through the above-mentioned agents. The Consent Form and a cover letter assured the families of the confidentiality of information they provided as well as solicited their cooperation in responding to the instrument. The instruments were numbered for identification purpose. The instruments were left with the educational institution, SS agency, itinerant teachers, and education consultants to be distributed to the families of HIC with whom they were in contact with. This procedure ensured that the families maintained anonymity while participating in the study. After approximately two weeks, follow-up letters (Appendix M) and the instrument were sent to the families through the educational institution, SS agency, itinerant teachers and educational consultants.

The respondents were asked to access the clarity, adequacy, understandability, and usefulness only of the information they received about SS. Thus, one type of information was obtained: how satisfied the 71 families were with the information provided to them.

Step 6: Findings

The analyses of responses of the 71 parents yielded results that suggest that the instrument is useable. The number of parents indicating that they had received information about the 16 aspects of support services varied across each support service aspect. The number ranged from 12 (counseling information for other family members) to 71 (collaboration with service providers). The means of their responses ranged from 15.2 (cochlear implants) to 30.8 (collaboration). The variation among the means reflects the different perceptions of the parents who had received information about support services held or felt about that information. The median number of parents that indicated that they received information about these aspects of support services was 36 (50.7%). This means that half of the parents had received information about all the 16 aspects of support services. Inspection of the statistics reveals that the 16 aspects had an acceptable level of internal consistency, ranging from 0.81 to 0.98. This provides initial evidence that the instrument worked properly in that the respondents to each set of items were consistent in their responses. Further, strong validity support for the items on the SSISI was also found from the responses of the panel of experts (see Chapter Four). They rated each of the items on the instrument highly and indicated that the list of services was comprehensive and complete. In addition, as illustrated in the discussion following presentation of the results for each aspect of support service information provided (see Chapter 5), the findings reflected well on other findings and issues found in the literature.

Limitations of the Study

Nonetheless, a number of issues deserve consideration in connection with the potential research and clinical utilization of this instrument. Although the findings of this study indicate that the SSISI can yield reliable data, it is a self-report measure and as such is vulnerable to the general limitations of all self-report measurement devices. All the items on the SSISI are direct and obvious in their intent. The danger inherent in this is that respondents can easily engage in "impression management" by making themselves appear as free of or laden with problems as they wish (Faul & Hudson, 1999). An attempt to avoid this problem was made by ensuring anonymity; no family can be identified.

A second problem is that a self-report measure such as the SSISI gathers the families' subjective evaluation of information about support services. Further, the families' perceptions of SS information may themselves be limited, because, for example, the families may never have had the experience or awareness of the existence of certain SS. Comments written on the instrument by some respondents, for example, "What does a social worker for the deaf do?" (Questionnaire #24), and "What are assistive listening devices?" (Questionnaire #37) amply illustrate this point. Indeed, the numbers of families indicating that they had received information about some of the aspects of support services was quite low. These limitations notwithstanding, the evidence from this study provides a strong initial basis for recommending the use of the SSISI in clinical and research applications concerned with providing meaningful information about SS to families with children with hearing loss.

Implications for Research and Improving the Instrument

Further research involving a larger subpopulation of families with children with hearing loss is needed to determine whether the instrument developed here is generalizable for use with different samples in different settings. Thus far, little evidence has been gathered to guide more effective means of disseminating information about support services to families with HIC. Research into more effective means of ensuring that families with newly diagnosed HIC are provided unbiased and balanced information about the developmental needs of their children and their roles in ensuring the success of intervention programs is urgent. Further, research into strategies that training programs can utilize to enhance the effectiveness of service providers in providing information about SS to families with HIC is needed. Although many well-intentioned and very hard-working professionals are providing services to HIC and their families, the lack of essential skills and knowledge on the part of professionals might be a factor precluding the provision of adequate and unbiased information about the developmental needs of HIC and SS to families. Therefore, research into the skill, experience, and training of service providers should explore how these factors affect the quality and quantity of information these professionals provide to families with HIC.

The present study should be replicated with specific groups of families with HIC. The instrument did not yield information that can permit comparing differences between groups of families with HIC in terms of gender, age, race and ethnicity, marital status, socio-economic status or family income, and level of education. In future research application of this instrument, the "Background Information" section should be expanded to include the above socio-demographic characteristics. This will make it possible to obtain data that can be used to compare different groups of families with HIC. It was not possible to do these in the present study due to constraints of time and resources.

The present study should be expanded with qualitative inquiries into the perspectives of parents with HIC in urban, suburban and rural localities of the information they had received about SS, with more variation in the sample (e.g., the inclusion of siblings and other family members). Parents might be requested to participate in focus groups to further discuss the emerging themes, and to provide them the opportunity to review the focus group interview transcripts. Future research should examine how the findings of this present study apply to non-urban parents, their children and other family members. All the parents who participated in the present study were resident in urban areas. How would the perspectives of the parents and other family members be different if they were from a rural area? Further research in this area could also contribute additional insight into the impact of urban environment.

Future studies might require multiple investigators for investigator triangulation. That is, data should be obtained from parents, siblings, other family members and professionals about their different perspectives of information about support services. Findings from such studies can contribute further to the knowledge of service providers and enhance their ability to provide unbiased, clear, adequate, understandable and useful information to families with HIC.

Conclusions

What led me to conduct the present study were the tremendous struggles of families with HIC as they seek information about services essential to the developmental needs of their children. I had first-hand experience of such struggles. After I lost my hearing at the age of 10, my parents spent three years taking me from one service provider to another. With no previous experience of hearing loss in the family, they remained confused about the different information they received from different professionals concerning my developmental needs. It was after three years that one of the service providers suggested we visit a school for deaf children. My parents were impressed with what they saw there. They realized immediately that I could continue my education there. That was how I enrolled in the school.

Those three years I remained at home while we were going from one service provider to another were periods of opportunity lost to me. If I had not already acquired language skills prior to losing my hearing, my language, cognitive, emotional, and social development would probably have been irreversibly and adversely affected.

It remains the case that the vast majority of HIC have not mastered societal language prior to losing their hearing. Without adequate, clear, understandable, and useful information about these children's developmental needs and SS available to support them, families with HIC may be unable to take positive and effective actions to obtain the services that will enhance the development of these children. Consequently, intervention services may be delayed, causing irreversible harm to many aspects of the children's development.

Described in the present study was an instrument that could provide information concerning the parental perceptions of the information they had received about support services. Given clear, adequate, understandable and useful information about these services, parents with HIC have the potential to obtain services essential to the developmental needs of their children. The provision of unbiased and adequate information to parents with HIC by service providers is fundamental to achieving this goal. It is up to service providers to ensure that relevant information about support services is provided to families with HIC in a timely manner. The stakes are too high to permit anything less.

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Appendix A

Table of Specification - Support Service Information Satisfaction Inventory

Service Domain	Questions
Diagnosis of hearing loss	1. Information about the cause of hearing loss
	2a. Clarity of the information
	b. Adequacy of information
	c. Understandability of the information
	d. Usefulness of the information
Coping strategies	3. Provision of coping strategies
	4a. Understanding of coping strategies
	b. Clarity of coping strategies information
	c. Adequacy of coping strategies
	d. Usefulness of the coping strategies
Counseling	5. Getting counseling
	6a. Clarity of counseling procedures
	b. Understandability of counseling procedures
	c. Adequacy of counseling
	d. Usefulness of counseling
	7. Availability of counseling to other family members
	8a. Adequacy of counseling for other family members
	b. Clarity of counseling given to other family members
	c. Understandability of counseling for other family members
	d. Usefulness of counseling to other family members.
Child's communication needs	9. Provision of information about child's communication needs
	10a. Understandability communication needs information
	b. Clarity of communication needs information
	c. Adequacy of communication needs information
	d. Usefulness of communication needs information

Sign language	11. Sign language course information
	12a. Clarity of sign language course information
	b. Understandability of sign language course information
	c. Adequacy of sign language course information
	d. Usefulness of sign language course information
Speech and language therapy	13. Speech and language therapy information
	14a. Clarity of speech and language therapy information
	b. Adequacy of speech and language therapy information
	c. Understandability of speech and language therapy information
	d. Usefulness of speech and language therapy information
Hearing Aids	15. Hearing aids information
	16a. Adequacy of hearing aids information
	b. Understandability of hearing aids information
	c. Clarity of hearing aids information
	d. Usefulness of hearing aids information
Assistive listening devices	17. Assistive listening devices information
	18a. Usefulness of assistive listening devices information
	b. Understandability of assistive listening devices information
	c. Clarity of assistive listening devices information
	d. Adequacy of assistive listening devices information
Education options	19. Education options information
	20a. Clarity of education options information
	b. Understandability of education options information
	c. Adequacy of education options information
	d. Usefulness of education options information

Deaf Culture and community information	21. Deaf culture and community
	22a. Understandability of deaf culture and community information
	b. Clarity of deaf culture and community information
	c. Usefulness of deaf culture and community information
	d. Adequacy of deaf culture and community information
Family support network	23. Family support network information
	24a. Clarity of family support network information
	b. Understandability of family support network information
	c. Adequacy of family support network information
	d. Usefulness of family support network information
Collaboration	25a. Listening professionals
	b. Caring and considerate professionals
	c. Sensitivity to concerns
	d. Involvement in decision-making
	e. Provision of feedback encouraged
	f. Consideration of feedback
Usefulness and Impact	26. Ability to obtain needed services
	27. Extent of ability to obtain needed services
	28. Impact of services received on family life
	29. Extent of impact of services received on family life
	30. Impact of services received on ability to care for child
	31. Extent of impact of services received on ability to care for child
Involved professionals	32a. Audiologists
	b. Speech and language therapists
	c. Teachers of the deaf
	d. Teacher aides for the deaf
	e. Regular school teachers
	f. Rehabilitation specialists
	g. Psychologists
	h. Social workers for the deaf
	i. Others (to specify).

Appendix B: First Draft of the Instrument

Support Service Information Satisfaction Inventory

Instruction

This scale is designed to assess whether or not you and your family received adequate information about support services from professionals to meet the developmental needs of your child(ren) with hearing loss. For each item, please **circle** the response that best describes the extent to which you considered that the information you received was clear, adequate, understandable and useful.

Diagnosis of Hearing Loss

1. Were you provided with information about the cause(s) of your child's hearing loss?

_______ Yes _______ No (Please to question 3)

2. How satisfied were you with the information about the cause(s) of hearing loss provided to you? Please circle the number that best reflects your satisfaction for each of the following four dimensions:

a. Very clear	1	2	3	4	5	6	7	Very unclear
b. Totally inadequate	1	2	3	4	5	6	7	Totally adequate
c. Not at all understandable	1	2	3	4	5	6	7	Very understandable
d. Very useful	1	2	3	4	5	6	7	Not at all useful

Coping Strategies

3. Were you provided with information about strategies for coping with negative feelings you had when you first learned that your child had a hearing loss?

_______ Yes ________ No (Please go to question 5)

4. How satisfied were you with the information and coping strategies provided to you? Please circle the number that best reflects your degree of satisfaction:

a. Very Understandable	1	2	3	4	5	6	7	Not at all understandable
b. Very unclear	1	2	3	4	5	6	7	Very clear
c. Totally adequate	1	2	3	4	5	6	7	Totally inadequate
d. Not at all useful	1	2	3	4	5	6	7	Very useful

Counseling

5. Have you received information about counseling for your child's hearing loss?

______ Yes _______ No (Please go to question 7)

6. How satisfied are you with the counseling information about your child's hearing loss? Please circle the number that best reflects your degree of satisfaction with the counseling information provided to you. Please consider each dimension:

a. Very clear	1	2	3	4	5	6	7	Very unclear
b. Not at all understandable	1	2	3	4	5	6	7	Very understandable
c. Totally inadequate	1	2	3	4	5	6	7	Totally adequate
d. Very useful	1	2	3	4	5	6	7	Not at all useful

7. Has counseling information been made available to other members of your family?

_______ Yes _______ No (Please go to question 9)

8. How satisfied are you with the counseling information given to other members of your family? Please circle the number that best reflects your degree of satisfaction:

a. Totally inadequate	1	2	3	4	5	6	7	Totally adequate
b. Very clear	1	2	3	4	5	6	7	Very unclear
c. Not at all								

understandable	1	2	3	4	5	6	7	Very understandable
d. Very useful	1	2	3	4	5	6	7	Not at all useful

Communication Needs

9. Have you received information about your child's communication needs?

________ Yes _______ No (Please go to question 11)

10. How satisfied are you with the information about your child's communication needs. Please circle the number that best reflects your degree of satisfaction for each of the following dimensions:

a. Very understandable	1	2	3	4	5	6	7	Not at all understandable
b. Not at all clear	1	2	3	4	5	6	7	Very clear
c. Totally adequate	1	2	3	4	5	6	7	Totally inadequate
d. Not at all useful	1	2	3	4	5	6	7	Very useful

Sign Language

11. Have you received information about a course in sign language?

_______ Yes ______ No (Please go to question 13)

12. How satisfied are you with the information about a sign language course? Please circle the number that best reflects your degree of satisfaction:

a. Very clear	1	2	3	4	5	6	7	Very unclear
b. Not at all understandable	1	2	3	4	5	6	7	Very understandable
c. Totally inadequate	1	2	3	4	5	6	7	Totally adequate
d. Very useful	1	2	3	4	5	6	7	Not at all useful

Speech and Language Therapy

13. Have you received information about speech and language therapy services?

_______ Yes ________ No (Please go to question 15)

14. How satisfied are you with the information about speech and language therapy services? Please circle the number that best reflects your degree of satisfaction for each of the following dimensions:

a. Very unclear	1	2	3	4	5	6	7	Very clear
b. Totally adequate	1	2	3	4	5	6	7	Totally inadequate
c. Not at all understandable	1	2	3	4	5	6	7	Very understandable
d. Very useful	1	2	3	4	5	6	7	Not at all useful

Hearing Aids

15. Have you received information about hearing aids?

________ Yes _______ No (Please go to question 17)

16. How satisfied are you with the information about hearing aids? Please circle the number that best reflects your degree of satisfaction:

a. Totally adequate	1	2	3	4	5	6	7	Totally inadequate
b. Not at all understandable	1	2	3	4	5	6	7	Very understandable
c. Very clear	1	2	3	4	5	6	7	Very unclear
d. Very useful	1	2	3	4	5	6	7	Not at all useful

Assistive Listening Devices

17. Have you received information about other assistive listening devices (for example, flashing door bells, telephone flashers)?

________ Yes _______ No (Please go to question 19)

18. How satisfied are you with the information about assistive listening devices?

Please circle the number that best reflects your degree of satisfaction. Please consider each of the following dimensions:

a. Very useful	1	2	3	4	5	6	7	Not at all useful
b. Not at all understandable	1	2	3	4	5	6	7	Very understandable
c. Very clear	1	2	3	4	5	6	7	Not at all clear
d. Totally inadequate	1	2	3	4	5	6	7	Totally adequate

Educational Options

19. Have you received information about the educational options for your child with hearing loss?

________ Yes ________ No (Please go to question 21)

20. How satisfied are you with the information about educational options? Please circle the number that best reflects your degree of satisfaction with the for each of the following four dimensions:

a. Very clear	1	2	3	4	5	6	7	Very unclear
b. Not at all understandable	1	2	3	4	5	6	7	Very understandable
c. Totally inadequate	1	2	3	4	5	6	7	Totally adequate
d. Very useful	1	2	3	4	5	6	7	Not at all useful

Deaf Culture and Community

21. Have you received information about deaf culture and community?

________ Yes ________ No (Please go to question 23)

22. How satisfied are you with the information about deaf culture and community? Please circle the number that best reflects your degree of satisfaction:

a. Not at all understandable	1	2	3	4	5	6	7	Very understandable
b. Very clear	1	2	3	4	5	6	7	Not at all clear
c. Not at all useful	1	2	3	4	5	6	7	Very useful
d. Totally adequate	1	2	3	4	5	6	7	Totally inadequate

Formal Support Resources

23. Have you received information about available formal helpful resources (for example, Connect Society, Glenrose Hospital) for families of children with hearing loss?

______ Yes __________ No (Please go to question 25)

24. How satisfied are you with the information about these helpful resources? Please circle the number that best reflects your degree of satisfaction for each of the following four dimensions:

a. Very understandable	1	2	3	4	5	6	7	Not at all understandable
b. Not at all useful	1	2	3	4	5	6	7	Very useful
c. Very clear	1	2	3	4	5	6	7	Not at all unclear
d. Totally inadequate	1	2	3	4	5	6	7	Totally adequate

Collaboration

25. How satisfied are you with the professionals providing services to you and your family? Please circle the number that best reflects your degree of satisfaction for each of the following domains:

a. Willingness to listen to you:

Not at any time 1 2 3 4 5 6 7 All of the time

b. Caring and considerate:

All of the time 1 2 3 4 5 6 7 Not at any time

c. Sensitive to your concerns:
Not at any time 1 2 3 4 5 6 7 All of the time

d. Involved you in making decisions about your child with hearing loss:
All of the time 1 2 3 4 5 6 7 Not at any time

e. Encouraged you to provide feedback on the services given to you:
Not at any time 1 2 3 4 5 6 7 All of the time

f. Considered the feedback you provided in making their decisions:
All of the time 1 2 3 4 5 6 7 Not at any time

Usefulness and Impact

26. Have you been able to obtain the services your child requires as a result of the information you have received?
_________Yes _______No (Please go to question 28)

27. To what extent have you been able to obtain the services your child requires? Please circle the number that best reflects your degree of satisfaction:

Not at any time 1 2 3 4 5 6 7 All of the time

28. Have the information and services you have been able to obtain for your child with hearing loss improved your family life?
__________ Yes ___________ No (Please go to question 30)

29. To what extent have the information and services you have received for your child improved your family life? Please circle the number that best reflects your degree of satisfaction:

A great deal 1 2 3 4 5 6 7 Not at all

30. Have the information and services you have received increased your ability to care for your child with hearing loss?
__________ Yes ___________ No (Please go to question 34)

31. How well have the information and services you have received increased your ability to care for your child with hearing loss? Please circle the number that best reflects your degree of satisfaction:

Not at all well 1 2 3 4 5 6 7 Very well

32. Which of the following professionals have worked with you (Please tick all that apply)

Audiologists	_____YES	______NO
Speech and language therapists	_____YES	______NO
Teachers of the Deaf	_____YES	______NO
Teachers aides of the Deaf	______YES	______NO
Regular school teachers	______YES	______NO
Rehabilitation Specialists	______YES	______NO
Psychologists	______YES	______NO
Social workers for the Deaf	______YES	______NO

Others (Please specify) --

THANK YOU FOR TAKING TIME TO COMPLETE THIS QUESTIONNAIRE

Appendix C: Letter to Review Panel Members (On WCCSD Letterhead)

Dear,

RE: FAMILIES' PERCEPTIONS OF SUPPORT SERVICE INFORMATION FOR YOUNG CHILDREN WITH HEARING LOSSES: THE DEVELOPMENT AND VALIDATION OF A NEW MEASURE

We are writing to request your participation as one of the panel members to scrutinize a new measuring instrument we are developing that could be of value in evaluating families' opinions of information about support services provided for their young children with hearing losses.

It is anticipated that constructive evaluation of the new measure by the panel members would ensure that the new instrument is adequately valid for the purpose it has been developed. To review the new instrument for validity, the panel members will complete the following tasks:

(i) The Essential Features Rating Form: They will complete the Essential Features Rating Form (see Appendix J) using the new instrument (Appendix H) and Table of Specifications (Appendix K). Essentially, the reviewers will be required to determine whether relevant and essential information on support services for families with hearing impaired children is incorporated in the new instrument.

(ii) Main Features Rating Form: The reviewers will complete the Main Features Rating Form (see Appendix L). They will review and comment on the comprehensiveness, sequencing and desirability of the items on the new instrument, as well as the clarity or otherwise of these items.

(iii) Item Content Review Form: Using the Instruction for Item Content Review (Appendix M), the reviewers will complete the Item Content Review Form (Appendix N). The task of the reviewers will be to judge the degree fit between the items on the new instrument and the domains to which they referenced.

Two copies of Informed Consent Form are attached. This form guarantees your right to withdraw from our research at any time and that all information provided will be kept strictly confidential and used only for this study and in articles disseminating the results. If you accept to be on our panel, please sign and date these forms. One is for your records and the other one should be returned to us in the enclosed addressed envelope.

Your participation in the panel is very important and will be very much appreciated. If you would like more information or have any questions, please call Jonah Eleweke at 492 2212 (TTY) or Professor Michael Rodda at 492 8247.

We are thanking you in advance for your time.
Sincerely,

C. Jonah Eleweke, Graduate Student   Michael Rodda, Professor & Advisor.

Appendix D-i

Informed Consent Form for Instrument Review Panel Members

I agree to participate in the families' perceptions of support service information measuring instrument development study of C. Jonah Eleweke as one of the panel members reviewing the instrument. I understand that (1) I can withdraw at any point if I do not wish to continue participating in the study and all information provided by me will be destroyed, and (2) information I provide will be treated with complete confidentiality, anonymity and used only for the purpose of this and articles disseminating the results.

----------------------------- (Please do not print your name)

Signature

Date

Appendix D-ii

Informed Consent Form for Families Participating in the Pilot Study

I agree to participate in the families' perceptions of support service information measuring instrument development study of C. Jonah Eleweke as one of the families involved in the pilot trial of the instrument. I understand that (1) I can withdraw at any point if I do not wish to continue participating in the study and all information provided by me will be destroyed, and (2) information I provide will be treated with complete confidentiality, anonymity and used only for the purpose of this study and articles disseminating the results.

------------------------------ (Please do not print your name)
Signature

Date

Appendix D-iii

Informed Consent Form for Families Participating in the Field Testing

I agree to participate in the families' perceptions of support service information measuring instrument development study of C. Jonah Eleweke as one of the families involved in the field-testing of the instrument. I understand that (1) I can withdraw at any point if I do not wish to continue participating in the study and all information provided by me will be destroyed, and (2) information I provide will be treated with complete confidentiality, anonymity and used only for the purpose of this study and articles disseminating the results.

----------------------------- (Please do not print your name)
Signature

Date

Appendix E-i
Panel Members Experience and Qualifications Form (Professionals)

Please do not write your name on this Form

Sex: Male ___________ Female __________

Hearing Status: please circle one: (a) Hearing (b) Deaf (c) Hard of Hearing

Age range: (a) 21-25 (b) 25-30 (c) 31-35 (d) 36-40 (e) Other ________

Please indicate your profession (please tick only one)

Professionals	**Yes**	**No**
Audiologist		
Speech Pathologist		
Teacher of the Deaf		
Psychologist		
Social Worker		
Otologist (Ear Doctor)		
Multidisciplinary Team		
Other, please specify:		

Please indicate your highest educational qualification (circle one)

Diploma in --
B.Ed./B.Sc. in --
M.A./M.Ed./M.Sc. in -------------------------------------
Ph.D. in --
Other, please specify -----------------------------------

Do you have experience providing services to families of children with hearing loss?

Yes _______ No _________

If yes,

What year did you start working with the families? _________

How many years have you been involved in working with the families? ______

What type of services do you give to families of children with hearing loss?

____

____

____

Appendix E-ii
Panel Members Experience and Qualifications Form (Families)

Please do not write your name on this Form

Sex: Male ___________ Female __________

Hearing Status: please circle one: (a) Hearing (b) Deaf (c) Hard of Hearing

Age range: (a) 21-25 (b) 25-30 (c) 31-35 (d) 36-40 (e) Other ________

How old is your child with hearing loss? ________________

Did you receive services for your child from professionals in the field of hearing loss?

Yes __________ No ____________

If yes,

How soon after the diagnosis of your child's hearing loss did you begin receiving these
services?

____

Please indicate the professionals that provided services to you (please tick all that apply)

Professionals	**Yes**	**No**
Audiologist		
Speech Pathologist		
Teacher of the Deaf		
Psychologist		
Social Worker		
Otologist (Ear Doctor)		
Multidisciplinary Team		
Other, please specify:		

Please indicate your highest educational qualification (circle one)
Diploma in --
B.Ed./B.Sc. in --
M.A./M.Ed./M.Sc. in ------------------------------------
Ph.D. in ---
Other, please specify ------------------------------------

Appendix F
Forms for Panel Members' Consistence in Responses (Relevance and Representative ness – 2R Factor

Please do not write your name on this Form

ESSENTIAL FEATURES RATING FORM

Based on the Table of Specification provided, I agree that all the relevant outcomes of support services for families of children with hearing loss are incorporated in the Support Service Information Satisfaction Inventory (SSISI).

Yes ________ No ________

If no, I would like to see the following relevant outcomes **added**:

Based on the Table of Specification provided, I agree that all the essential outcomes of support services for families of children with hearing loss are represented in the Support Service Information Satisfaction Inventory (SSISI).

Yes _________ No _________

If no, I recommend that the following essential outcomes be **added**:

Note: Please feel free to use the back of this paper and extra sheets to make additional comments that could improve the SSISI

Appendix G
MAIN FEATURES RATING FORM

Please do not write your name on this Form

Comprehensiveness of the SSISI

I agree that the content of the SSISI is comprehensive.

Yes ------------ No ---------------

If no, I recommend the **addition** of following:

Comprehensiveness of the SSISI

I agree that all the items should be retained in the SSISI.

Yes -------------- No ------------------

If no, I recommend the **deletion** of the following:
Number Item
-------- ---
-------- ---
-------- ---
-------- ---
-------- ---
-------- ---
-------- ---
-------- --
-------- --
-------- --

Sequencing

I agree with the sequencing of the SSISI

Yes -------- No --------------

If yes, essential items are numbers ---

Desirable items are numbers --

If no, my sequence is:

Essential items are numbers --

Desirable items are numbers --

Clarity of writing

I agree that the items in the SSISI are clear and unambiguous.

Yes ------------ No --------------

If no, I would recommend the following changes:
Item # Recommended change
-------- ---
-------- ---
-------- ---
-------- ---
-------- ---
-------- ---
-------- ---
-------- ---

Appendix H-i
INSTRUCTION FOR ITEM CONTENT REVIEW

Please do not write your name on this Form

1. Please read carefully through the Table of Domain Specification and question items.

2. Indicate how well you feel each item reflects the domain specifications it has been written to measure.

Judge an item solely on the basis of the match between its content and the content defined in the domain specification that the item has been prepared to measure

Please use the five point rating scale shown below:

Poor	Fair	Good	Very Good	Excellent
1	2	3	4	5

Circle the number corresponding to your rating beside the test item, and add any comment you may wish.

Appendix H-ii
Item Content Review Form

Service Domain	Item No.	Item Rating					Comments
Diagnosis of Hearing loss	1	1	2	3	4	5	
	2a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Coping strategies	3	1	2	3	4	5	
	4a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Counseling	5	1	2	3	4	5	
	6a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
	7	1	2	3	4	5	
	8a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Child's communication Needs	9	1	2	3	4	5	
	10a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Sign language	11	1	2	3	4	5	
	12a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	

Service Domain	**Item No.**	**Item Rating**					**Comments**
Speech and language therapy	13	1	2	3	4	5	
	14a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Hearing Aids	15	1	2	3	4	5	
	16a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Assistive listening Devices	17	1	2	3	4	5	
	18a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Education options	19	1	2	3	4	5	
	20a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Deaf Culture and Community	21	1	2	3	4	5	
	22a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
Family support network	23	1	2	3	4	5	
	24a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	

Service Domain	Item No.	Item Rating					Comments
Collaboration	25a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
	e	1	2	3	4	4	
	f	1	2	3	4	5	
Usefulness and Impact	26	1	2	3	4	5	
	27	1	2	3	4	5	
	28	1	2	3	4	5	
	29	1	2	3	4	5	
	30	1	2	3	4	5	
	31	1	2	3	4	5	
Involved professionals	32a	1	2	3	4	5	
	b	1	2	3	4	5	
	c	1	2	3	4	5	
	d	1	2	3	4	5	
	e	1	2	3	4	5	
	f	1	2	3	4	5	
	g	1	2	3	4	5	
	h	1	2	3	4	5	
	i	1	2	3	4	5	

Appendix I
Support Service Information Satisfaction Inventory (SSISI) (Final Draft)

PART ONE

Background Information

City/Town of Residence ______________________________________

Your hearing status, please tick one:

__________Hearing ________Deaf _______Hard of Hearing

Your child's hearing status, please circle one:

_______ Deaf __________Hard of Hearing

How old is your child with hearing loss? _______________

How old was your child when the hearing loss was diagnosed?

____

Have you been receiving services for your child's needs from professionals in the field of hearing loss?

Yes __________ No _____________

If yes, how soon after the diagnosis of your child's hearing loss did you begin receiving these services?

____

How many years have you been receiving services from the professionals since your child's hearing loss was diagnosed?

____

PART TWO

Support Service Information Satisfaction Inventory

We would like to know how satisfied you are with the information about the various services that you may have received from various professionals to help meet the developmental needs of your child with a hearing loss. For each service that you have received, we would like you to indicate the degree of satisfaction you have with the information and service provided. Seven point scales are provided with descriptors at each end. Please circle the number that corresponds most closely to your level of satisfaction. Remember that there are no right or wrong answers. Instead, we want to know how satisfied you are with the (a) clarity, (b) understandability, (c) adequacy, and (d) utility of the information that have been provided to you and your family. Please read and answer each question completely and carefully. The information you provide will help to develop a new formal inventory that would be of value in evaluating the opinion of families with children with hearing loss on the information about support services provided to them for meeting the developmental needs of their children.

Diagnosis of Hearing Loss

1. Were you provided with information about the cause(s) of your child's hearing loss? **(Please circle)**

Yes No **(If no, proceed to Question 3)**

2. How satisfied were you with the information about the cause(s) of hearing loss provided to you? **(Please circle the number that best reflects your satisfaction for each of the following four dimensions)**

(a)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(b)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate
(c)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Coping Strategies

3. Were you provided with information about strategies for coping with negative feelings you had when you first learned that your child had a hearing loss?
(Please circle)

Yes No **(If no, proceed to Question 5)**

4. How satisfied were you with the information and coping strategies provided to you? **(Please circle the number that best reflects your degree of satisfaction.)**

(a)	Very Understandable	1	2	3	4	5	6	7	Not at all Understandable
(b)	Very Unclear	1	2	3	4	5	6	7	Very Clear
(c)	Totally Adequate	1	2	3	4	5	6	7	Totally Inadequate
(d)	Not at all Useful	1	2	3	4	5	6	7	Very Useful

Counseling

5. Have you receive information about counseling for your child's hearing loss?
(Please circle)

Yes No **(If no, proceed to Question 7)**

6. How satisfied are you with the counseling information about your child's hearing loss? **(Please circle the number that best reflects your degree of satisfaction with the counseling information provided to you. Please consider each dimension.)**

(a)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(b)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(c)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

7. Has counseling information been made available to other members of your family? **(Please circle)**

Yes No **(<u>If no</u>, proceed to Question 9)**

8. How satisfied are you with the counseling information given to other members of your family? **(Please circle the number that best reflects your degree of satisfaction.)**

(a)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate
(b)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(c)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Communication Needs

9. Have you received information about your child's communication needs? **(Please circle)**

Yes No **(<u>If no</u>, proceed to Question 11)**

10. How satisfied are you with the information about your child's communication needs? **(Please circle the number that best reflects your degree of satisfaction for each of the following dimensions.)**

(a)	Very Understandable	1	2	3	4	5	6	7	Not at all Understandable
(b)	Not at all Clear	1	2	3	4	5	6	7	Very Clear
(c)	Totally Adequate	1	2	3	4	5	6	7	Totally Inadequate
(d)	Not at all Useful	1	2	3	4	5	6	7	Very Useful

Sign Language

11. Have you received information about a course in sign language? **(Please circle)**

Yes No **(<u>If no</u>, proceed to Question 13)**

12. How satisfied are you with the information about a sign language course? **(Please circle the number that best reflects your degree of satisfaction.)**

(a)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(b)	Not at all	1	2	3	4	5	6	7	Very

Understandable

Understandable

(c)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Speech and Language Therapy

13. Have you received information about speech and language therapy services? **(Please circle)**

Yes No **(If no, proceed to Question 15)**

14. How satisfied are you with the information about speech and language therapy services? **(Please circle the number that best reflects your degree of satisfaction for each of the following dimensions.)**

(a)	Very Unclear	1	2	3	4	5	6	7	Very Clear
(b)	Totally Adequate	1	2	3	4	5	6	7	Totally Inadequate
(c)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Hearing Aids

15. Have you received information about hearing aids? **(Please circle)**

Yes No **(If no, proceed to Question 17)**

16. How satisfied are you with the information about hearing aids? **(Please circle the number that best reflects your degree of satisfaction.)**

(a)	Totally Adequate	1	2	3	4	5	6	7	Totally Inadequate
(b)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(c)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

17. Have you received information about cochlear implants? **(Please circle)**

Yes No **(<u>If no</u>, proceed to Question 19)**

18. How satisfied are you with the information about cochlear implants? **(Please circle the number that best reflects your degree of satisfaction.)**

(a)	Very Unclear	1	2	3	4	5	6	7	Very Clear
(b)	Very Understandable	1	2	3	4	5	6	7	Not at all Understandable
(c)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Assistive Listening Devices

19. Have you received information about other assistive listening devices (for example, flashing door bells, telephone flashers)?
(Please circle)

Yes No **(<u>If no</u>, proceed to Question 21)**

20. How satisfied are you with the information about assistive listening devices? **(Please circle the number that best reflects your degree of satisfaction. Please consider each of the following dimensions.)**

(a)	Very Useful	1	2	3	4	5	6	7	Not at all Useful
(b)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(c)	Very Clear	1	2	3	4	5	6	7	Not at all Clear
(d)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate

Educational Options

21. Have you received information about the educational options for your child with hearing loss?
(Please circle)

Yes No **(<u>If no</u>, proceed to Question 23)**

22. How satisfied are you with the information about educational options? **(Please circle the number that best reflects your degree of satisfaction with the for each of the following four dimensions.)**

(a)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(b)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(c)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Funding Resources

23. Have you received information about funding resources available to families with children with hearing loss?
(Please circle)

Yes No **(<u>If no</u>, proceed to Question 25)**

24. How satisfied are you with the information about funding resources? (Please circle the number that best reflects your degree of satisfaction with the for each of the following four dimensions.)

(a)	Totally Adequate	1	2	3	4	5	6	7	Totally Inadequate
(b)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(c)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Deaf Culture and Community

25. Have you received information about deaf culture and community?

(Please circle)

Yes No **(If no, proceed to Question 27)**

26. How satisfied are you with the information about deaf culture and community? **(Please circle the number that best reflects your degree of satisfaction.)**

(a)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(b)	Very Clear	1	2	3	4	5	6	7	Not at all Clear
(c)	Not at all Useful	1	2	3	4	5	6	7	Very Useful
(d)	Totally Adequate	1	2	3	4	5	6	7	Totally Inadequate

Informal Family Support Network

27. Have you received information about informal support network (example, groups of families) for families of children with hearing loss?

(Please circle)

Yes No **(If no, proceed to Question 29)**

28. How satisfied are you with the information about informal support network? **(Please circle the number that best reflects your degree of satisfaction for each of the following dimensions.)**

(a)	Very Clear	1	2	3	4	5	6	7	Very Unclear

(b)	Not at all Understandable	1	2	3	4	5	6	7	Very Understandable
(c)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate
(d)	Very Useful	1	2	3	4	5	6	7	Not at all Useful

Formal Support Resources

29. Have you received information about available formal helpful resources (for example, Connect Society, Glenrose Hospital) for families of children with hearing loss? **(Please circle)**

Yes No **(If no, proceed to Question 31)**

30. How satisfied are you with the information about other helpful resources? **(Please circle the number that best reflects your degree of satisfaction for each of the following four dimensions.)**

(a)	Very Understandable	1	2	3	4	5	6	7	Not at all Understandable
(b)	Not at all Useful	1	2	3	4	5	6	7	Very Useful
(c)	Very Clear	1	2	3	4	5	6	7	Very Unclear
(d)	Totally Inadequate	1	2	3	4	5	6	7	Totally Adequate

Collaboration

31. How satisfied are you with the professionals providing services to you and your family? **(Please circle the number that best reflects your degree of satisfaction for each of the following domains.)**

(a) Willingness to listen to you:

Not at any time 1 2 3 4 5 6 7 All of the time

(b) Caring and considerate:

All of the time 1 2 3 4 5 6 7 Not at any time

(c) Sensitive to your concerns:

Not at any time 1 2 3 4 5 6 7 All of the time

(d) Involved you in making decisions about your child with hearing loss:

All of the time 1 2 3 4 5 6 7 Not at any time

(e) Encouraged you to provide feedback on the services given to you:

Not at any time 1 2 3 4 5 6 7 All of the time

(f) Considered the feedback you provided in making their decisions:

All of the time 1 2 3 4 5 6 7 Not at any time

Usefulness and Impact

32. Have you been able to obtain the services your child requires as a result of the information you have received?
(Please circle)

Yes No **(<u>If no</u>, proceed to Question 34)**

33. To what extent have you been able to obtain the services your child requires? **(Please circle the number that best reflects your degree of satisfaction.)**

Not at any time 1 2 3 4 5 6 7 All of the time

34. Have the information and services you have been able to obtain for your child with hearing loss improved your family life?
(Please circle)

Yes No **(If no, proceed to Question 36)**

35. To what extent have the information and services you have received for your child improved your family life? **(Please circle the number that best reflects your degree of satisfaction.)**

A great deal 1 2 3 4 5 6 7 Not at all

36. Have the information and services you have received increased your ability to care for your child with hearing loss?
(Please circle)

Yes No **(If no, proceed to Question 38)**

37. How well have the information and services you have received increased your ability to care for your child with hearing loss? **(Please circle the number that best reflects your degree of satisfaction.)**

Not at all well 1 2 3 4 5 6 7 Very well

38. Which of the following professionals have worked with you? **(Please circle all that apply.)**

Audiologists	Yes	No
Speech and Language Therapists	Yes	No
Teachers of the Deaf	Yes	No
Teachers Aides of the Deaf	Yes	No
Regular School Teachers	Yes	No
Rehabilitation Specialists	Yes	No
Psychologists	Yes	No
Social Workers for the Deaf	Yes	No
Educational Consultants	Yes	No
Interpreters	Yes	No
Special Education Assistants	Yes	No
Others **(Please specify)**	______________________________	

THANK YOU FOR TAKING TIME TO COMPLETE THIS QUESTIONNAIRE

Appendix J: Letter to Families Participating in the Pilot Study
(On WCCSD Letterhead)

Dear Parent(s)

RE: FAMILIES' PERCEPTIONS OF SUPPORT SERVICES INFORMATION FOR YOUNG CHILDREN WITH HEARING LOSS: THE DEVELOPMENT AND VALIDATION OF A NEW MEASURE

Please find enclosed a new measuring instrument we have developed that could be of value in evaluating families' opinions of information about support services provided for children and young people with hearing losses. Your kind assistance is solicited in the validation of the instrument. At this stage we are trying out the inventory with a view to modification. You are encouraged to make comments and suggestions concerning directions, recording procedures, and specific items in the inventory. The feedback from you will be kept confidential and used strictly to revise the inventory.

Please do not write your name on this questionnaire. Two copies of Informed Consent Form are attached. This form guarantees your right to withdraw from our research at any time and that all information provided will be kept strictly confidential and used only for this study and in articles disseminating the results. Please sign and date these forms. One is for your records and the other one should be returned to us with your completed questionnaire in the enclosed addressed envelope. If you would like more information or have any questions, please call Jonah Eleweke at 492 2212 (TTY) or Professor Michael Rodda at 492 8247.

Thank you for your time and assistance.

Sincerely,

C. Jonah Eleweke	Michael Rodda, Professor
Graduate Student	Advisor

Appendix K: Letter to Agencies (On WCCSD Letterhead)

Dear

RE: FAMILIES' PERCEPTIONS OF SUPPORT SERVICE INFORMATION FOR CHILDREN WITH HEARING LOSS: THE DEVELOPMENT AND VALIDATION OF A NEW MEASURE

We are conducting a research into the development and validation of a new formal inventory that could be of value in evaluating families' opinions of support services provided for children and young people with hearing losses. Support services are expected to enable the families concerned to accept, understand and meet these children's special needs. Such services include assisting families cope with the diagnosis of hearing loss in their child, providing relevant information to families, enhancing their participation in early intervention programs, as well as the educational development of their children, and collaborating meaningfully with professionals providing these services.

Apart from ensuring that valid and reliable information is obtained from families, the new instrument will have implications for intervention purposes in that a family's responses could be the basis for discussion and intervention planning. Consequently, the new instrument could be of immense benefit to organizations such as yours involved in the provision of support services to families of children with hearing loss.

It would be very much appreciated if your organization could assist us in contacting the families of children and young people with hearing losses receiving services from your agency to participate in this important instrument validation study. We would like to know the number of such families you are providing services. We will then send the instrument that we have developed to you to assist us in sending to the families. We will be responsible for the postal charges.

We look forward to reading from you in order to know the number of the new instrument to send to you for onward transmission to the families. Please find enclosed a self-addressed envelope to facilitate your response. All information will be kept completely confidential. If you would like more information or have any questions, please call Jonah Eleweke at 492 2212 (TTY) or Professor Michael Rodda at 492 8247.

With many thanks for your assistance

C. Jonah Eleweke Graduate Student	Michael Rodda, Professor Advisor

Appendix L: Letter to Families Participating in the Field Test (On WCCSD Letterhead)

Dear Parent(s),

RE: FAMILIES' PERCEPTIONS OF SUPPORT SERVICE INFORMATION FOR CHILDREN WITH HEARING LOSSES: THE DEVELOPMENT AND VALIDATION OF A NEW MEASURE

We are conducting a research into the development and validation of a new formal inventory that could be of value in evaluating families' opinions of information on support services provided for children with hearing losses. The information on these support services is expected to enable families to accept, understand and meet their children's special needs.

Apart from ensuring that valid and reliable information is obtained from families, the new instrument will have implications for intervention purposes in that a family's responses could be the basis for discussion and intervention planning. Consequently, the new instrument could be of immense benefit to families such as yours as it could facilitate the provision of the appropriate support services.

Your kind assistance is solicited in the validation of the instrument that we have developed and attached herewith. Filling this questionnaire will require about 20-30 minutes of your time. We'd like to thank you for the time spared to fill this instrument.

Please do not write your name on this questionnaire. Please answer all the questions objectively and thoroughly. Your honest responses and comments will contribute to the development of an important instrument that could provide a better understanding of the needs of families with young children with hearing losses and the extent to which the information on services provided to them is satisfactory in addressing these needs.

Two copies of Informed Consent Form are attached. This document guarantees your right to withdraw from our research at any time and that all information provided will be kept strictly confidential and used only for this study and in articles disseminating the results. Please sign and date these forms. One is for your records and the other one should be returned to us with your completed questionnaire in the enclosed addressed envelope. If you would like more information or have any questions, please call Jonah Eleweke at 492 2212 (TTY) or Professor Michael Rodda at 492 8247.

Thank you for your time and assistance.

C. Jonah Eleweke	Michael Rodda, Professor
Graduate Student	Advisor

Appendix M: Reminder to Families Participating in the Field Test (On WCCSD Letterhead)

Dear Parent(s),

RE: FAMILIES' PERCEPTIONS OF SUPPORT SERVICE INFORMATION FOR CHILDREN WITH HEARING LOSSES: THE DEVELOPMENT AND VALIDATION OF A NEW MEASURE

A packet containing the above named instrument was sent to you earlier this month. A big thank you if already you had completed and returned it to us it in the self-addressed envelope we enclosed. In that case, we apologize for sending this 'reminder', the instrument and Consent Forms again.

If, however, the questionnaire has not been filled due to constraints of time, we can understand. Nonetheless, we would be very grateful for the precious time you could spare to fill and return the instrument to us. Your responses to the questions on the instrument are very important and it would therefore be very much appreciated if this instrument could be filled and returned to us. Receiving your completed questionnaire soon would greatly assist us in moving our research forward.

A copy of the instrument previously sent is enclosed, just in case the first one could not be found. Also two copies of Informed Consent Form are attached. This form guarantees your right to withdraw from our research at any time and that all information provided will be kept strictly confidential and used only for this study and in articles disseminating the results. Please sign and date these forms. One is for your records and the other one should be returned to us with your completed questionnaire in the enclosed addressed envelope.

With many thanks for your kind assistance.

Sincerely,

C. Jonah Eleweke	Michael Rodda, Professor
Graduate Student	Advisor