

## ■ A Framework for Research and Practice in Infant Hearing

## ■ Cadre de travail pour la recherche et la pratique concernant les troubles de l'audition chez les enfants

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### Abstract

Population-based infant hearing screening has received worldwide attention as an opportunity to improve communication development outcomes for children with hearing loss. While there is evidence that screening can accurately identify infants, less information is available on the effectiveness of early intervention and how to maximize these new opportunities. This paper presents a framework for research and practice in infant hearing. Using the International Classification of Functioning, Disability and Health model as a starting point, this research applied a population health perspective to develop a framework to guide clinical practice and research. The framework was refined on the basis of the literature as well as research relative to the benefits of newborn screening including parents' perspectives of benefits and needs. The new framework defines outcomes from the perspective of families and highlights contextual factors such as access to parent support and coordinated services, which may be important determinants of outcome to consider in program evaluation. Newborn hearing screening programs have received support on the basis that earlier identification of hearing loss will lead to improved communication results. This framework expands these outcomes and can inform the implementation of population hearing screening programs as they continue to expand worldwide.

### Abrégé

Le dépistage au sein de la population des troubles auditifs chez les enfants a été perçu dans le monde entier comme une occasion d'améliorer les perspectives de développement de la communication chez les enfants ayant des pertes auditives. Alors qu'il est clair que le dépistage permet d'identifier avec exactitude les troubles auditifs chez les bébés, on retrouve moins d'information sur l'efficacité d'une intervention précoce et sur la façon de maximiser ces nouvelles occasions. Cet article présente un cadre de travail pour la recherche et la pratique concernant les troubles de l'audition chez les enfants. En se référant au modèle de la Classification internationale du fonctionnement, du handicap et de la santé, cette recherche a utilisé le point de vue de la santé publique pour élaborer un cadre afin de guider la pratique et la recherche cliniques. Le cadre a été mis au point à l'aide de la documentation et des recherches concernant les avantages du dépistage chez les nouveaux nés, ainsi que de la vision des parents quant aux besoins et bénéfices. Le nouveau cadre définit les performances du point de vue des familles et souligne les facteurs contextuels tels que le soutien aux parents et les services coordonnés, lesquels peuvent jouer un rôle important au niveau des performances et doivent être considérés dans l'évaluation du programme. Les programmes de dépistage de troubles auditifs chez les nouveaux nés ont reçu beaucoup de considérations, car on croit que l'identification précoce de perte auditive mènera à de meilleures performances en communication. Ce cadre détaille ces performances et donne des renseignements sur la mise en œuvre de programmes de dépistage de troubles auditifs au sein de la population. Ces derniers continuent d'ailleurs de prendre de l'essor mondialement.

**Key words:** infant hearing, screening, hearing loss, parents, qualitative research

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Childhood hearing impairment has received increasing attention as a public health issue in the last decade. Hearing loss is one of the most common congenital disorders, affecting 1 to 3 per 1000 children (Fortnum, Summerfield, Marshall, Davis, & Bamford, 2001; Prieve & Stevens, 2000) and can have negative consequences for language, social and academic development. Newborn hearing screening (NHS) has become an important population health intervention aimed at improving the health and education outcomes for children with hearing loss and their families (Joint Committee on Infant Hearing, 2007). Several studies provide support for the benefits of early detection and intervention in achieving better communication outcomes in children with hearing loss (Calderon & Naidu, 2000; Kennedy et al., 2006; Moeller, 2000; Yoshinaga-Itano, Sedley, Coulter, & Mehl, 1998). It is well recognized that screening in itself is insufficient to improve developmental outcomes, that early intervention is crucial to a successful early hearing detection program and that detection without intervention may be of limited value (Jerger, Roeser, & Tobey, 2001; Joint Committee on Infant Hearing, 2007; Yoshinaga-Itano, 2004). It is recommended that newborn hearing screening be embedded in a system of comprehensive family-oriented care that includes the identification of hearing loss, family counseling, fitting of technology and intervention (Canadian Working Group on Childhood Hearing, 2005).

Newborn hearing screening initiatives share the characteristics of many population-based interventions in that they essentially become multiple intervention programs, targeting many levels in the system. Multiple intervention programs are initiatives that target changes (outcomes) at multiple levels (Edwards, Mill, & Kothari, 2004) in that strategies are directed not only at the individual level but at different levels of the socio-ecological system and are delivered to multiple audiences. Hearing screening, in its very simple form, may be viewed as a single intervention aimed at lowering the age of identification of congenital hearing loss for an individual baby. However, as a population health intervention, the ultimate goal of NHS is to improve health outcomes and reduce disparities across members of a population. Increasingly, there is a realization that infant hearing screening cannot be isolated from the subsequent management of hearing loss and family supports (Hyde, 2005; Yoshinaga-Itano, 2004). Accordingly, many NHS initiatives have also targeted deliberately or indirectly changes at structural levels of care, for example, at a programmatic level in terms of resources for additional clinical training and clinical equipment, and at a systemic level in terms of facilitating access to high quality pediatric audiologic services and reducing wait times when there is suspicion of hearing loss (Bamford, Uus, & Davis, 2005; Hyde, 2005). Parents also describe changes such as easier access to diagnostic and rehabilitative audiologic services as benefits of infant hearing screening initiatives (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007). In applying resources to NHS, modifications have been made to the process of infant hearing care that extend

well beyond the mere introduction of screening and the subsequent lowering of age of confirmation of hearing loss. Consequently, when NHS projects are envisioned as multiple interventions, the evaluation of the effectiveness of universal screening programs becomes complex and measuring outcomes using traditional research paradigms can be challenging.

### Effectiveness of newborn hearing screening

The historical focus of evaluating the effectiveness of NHS has been on speech and language outcomes (Thompson et al., 2001; Yoshinaga-Itano, 2003a, 2003b). Although there is a considerable body of literature substantiating the effectiveness of population screening for the early detection of childhood hearing loss, the evidence for a clear association between early identification and future communication skills remains inconclusive (Thompson et al., 2001). While some studies have shown an association between age of identification of hearing loss and improved communication outcomes (Kennedy et al., 2006; Yoshinaga-Itano et al., 1998), others have not been able to demonstrate a clear relationship between age of confirmation and speech-language development (Fitzpatrick, Durieux-Smith, Eriks-Brophy, Olds, & Gaines, 2007; Wake, Poulakis, Hughes, Carey-Sargeant, & Rickards, 2005). Such indicators of outcome are typically indirect or partial measures of a complex intervention (Casebeer, Deis, & Daze, 1999). Several researchers have recognized that screening is the first step in a comprehensive care process to minimize the impact of childhood hearing loss on individuals and society. Previous research has served to point out that many child, family and contextual factors may affect communication development (Calderon, 2000; Moeller, 2000; Yoshinaga-Itano, 2003a). Consequently, there has been a shift in the dialogue and more recently, investigators have questioned whether speech and language measures should be the ultimate outcome for evaluating the effectiveness of newborn hearing screening (Durieux-Smith, Fitzpatrick, & Whittingham, 2008; Hyde, 2005).

### Family oriented services

Consistent with the escalation of NHS initiatives in Canada and elsewhere, interest has grown in evaluating the real world effectiveness and value of the intervention. The attention on NHS has prompted interest in examining the influence of other factors that work in concert with newborn screening to impact developmental outcomes in young children. The contribution of screening as one component of a hearing health services package aimed at reducing disability may be affected by many family and environmental factors. One such factor which has emerged and is attracting greater attention in the literature is family participation and the ability of the system to meet family needs. In a study of outcomes in early and late identified children, parental involvement was identified as an important predictor of communication outcomes (Moeller, 2000). Recently, a series of studies from the evaluation of the newly implemented newborn hearing screening program in the United Kingdom (UK) emphasized the

importance of family perspectives and family perceived outcomes at various stages in the screening and early assessment process (Tattersall & Young, 2006; Young & Tattersall, 2005; Young & Tattersall, 2007). Professional communication and manner were reported to be the most significant predictors of parents' perspectives of their experiences during the diagnostic process in audiology and medical clinics.

There is also a growing recognition that overall infrastructure and resources related to intervention are critical to positive outcomes in newborn hearing screening initiatives. As the UK embarked on a national screening program, challenges in service provision were identified through a national study of preschool services in which parents identified well-coordinated and high quality services as fundamental to "family friendly" care (Robinson & Evans, 2003). Pairing newborn screening initiatives with quality early intervention in a family friendly context has been described as one of the most important challenges to the success of newborn hearing screening initiatives (Kennedy, 2000).

The implementation of newborn hearing screening represents a paradigm shift where services are moving to more family-oriented approaches with greater inclusion of parents in care and decision-making. There is some evidence from other areas of health care to support that in addition to the actual outcomes of intervention, the process of receiving care is important for individuals (Ratcliffe & Buxton, 1999; Ryan, 2000). There is also evidence from pediatric rehabilitation to suggest that patient satisfaction is related to both the actual care process (i.e., technical competence and quality of care) and organizational aspects of the service delivery model (King, Cathers, King, & Rosenbaum, 2001).

During the early development of NHS initiatives, attention was focused on the effectiveness of screening techniques (e.g., electro-physiologic screening measures) and yield of screening programs in order to provide an evidence-base for universal screening. There is a growing understanding that other aspects of post-screening care such as the appropriateness of service delivery models for families can have an important impact of the outcomes of newborn screening initiatives. The abilities of parents to participate in intervention programs through attendance at a clinic or even in home-based settings may be related to many factors including culture, socio-economic circumstances, geographical disparities, beliefs and supports. Even in countries with socialized medicine, the ability to navigate waiting lists, attend therapy sessions, and pay for certain services such as hearing aids are influenced by individual family resources (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008). These contextual factors, which have received less attention than age of diagnosis in the literature, may place children at risk for poor outcomes despite the potential advantages of early diagnosis through population screening, and may be important determinants of outcome in children with hearing impairment (Watkin et al., 2007).

## Rationale and Purpose

Several years ago, the United States Preventive Services Task Force, through a systematic review, concluded that newborn hearing screening leads to earlier diagnosis but that the evidence for improved communication outcomes was inconclusive (Thompson et al., 2001). The review identified the need for an examination of other benefits of screening and noted that there was insufficient evidence to draw conclusions about any potential process outcomes or other benefits for families resulting from early diagnosis and intervention. It has become increasingly clear that screening to improve infant development cannot be detached from intervention services. As indicated in several reports, the effectiveness of newborn hearing screening is intricately linked to the subsequent intervention process which includes audiologic assessment and rehabilitation for confirmed hearing loss (Canadian Working Group on Childhood Hearing, 2005; Joint Committee on Infant Hearing, 2007; Watkin et al., 2007; Yoshinaga-Itano, 2004). Therefore, screening is increasingly viewed as a procedure which must be anchored in a context of clinical support services for affected children and families.

The purpose of this paper is to propose a framework for infant hearing research that offers a structure for the next generation of research and practice in infant hearing screening. The framework was conceptualized based on a comprehensive literature review and the findings from a recent doctoral thesis which have been reported in a series of publications (Fitzpatrick, Durieux-Smith, et al., 2007; Fitzpatrick, Graham, et al., 2007; Fitzpatrick, Coyle, et al., 2007). This research examined the impact of early identification of hearing loss and factors affecting outcome both through objective communication development measures and through the perspective of parents. In particular, the work in this project centered on two broad domains: (a) the benefits of early identification including traditional communication outcomes and other benefits perceived by parents, and (b) aspects of the care model that are important to parents. Specifically, the research examined typical speech and language outcome measures and their contribution to understanding the benefits of early diagnosis of hearing loss. Secondly, the research was directed at identifying parents' perspectives of benefits, their needs for support, and their preferences for the attributes of rehabilitation care models. The overall goal was to examine the complex interaction between the child with hearing loss and numerous contextual factors to provide a more comprehensive perspective of health and well-being for children with hearing loss and their families.

Overall, these studies demonstrated that families of young children with hearing loss, regardless of whether they entered the process through newborn screening or not, value early identification initiatives as a core component of a system of infant hearing services. Although the effectiveness of screening in improving specific communication outcomes could not be quantified through objective measurement tools, (Fitzpatrick, Durieux-Smith, et al., 2007) these studies provided evidence that parents either experienced or

envisioned several positive child and family benefits from early identification. These perceived outcomes, which will be further discussed in the context of the framework, included access to hearing and improved self-esteem for the child as well as better access to care and reduced guilt for families (Fitzpatrick, Graham, et al., 2007). Through interviews and a conjoint analysis survey, parents highlighted well-coordinated services, support from other parents and access to information as important determinants of outcome (Fitzpatrick, Coyle, et al., 2007). These benefits from the perspectives of families, combined with the evidence in the literature for improved access to hearing, provide additional support for universal hearing screening. However, it is important to note that these studies were conducted in the context of a publicly funded health system where more than 90% of families with infants identified through NHS choose oral communication options (personal communication). Accordingly, the proposed framework is shaped by this focus on oral communication development and inclusion with hearing peers.

In addition, the framework was influenced by the research of several other investigators who have examined outcomes in communication development for children who are exposed to early detection and intervention (Calderon & Naidu, 2000; Kennedy et al., 2006; Moeller, 2000; Yoshinaga-Itano et al., 1998). These and other publications (Calderon, 2000; Robinshaw & Evans, 2003; Yoshinaga-Itano, 2004; Young & Andrews, 2001) serve to highlight the potential contribution of numerous other factors, including service provision and parental involvement, to infant hearing development.

The research described above forms the theoretical underpinnings of the model which attempts to both integrate current findings on outcomes in childhood hearing as well as identify factors that are associated with child and family outcomes. The framework is presented as a starting point for thinking about infant hearing in population health, practice and policy. The framework is discussed and interpreted in relation to the conceptual framework of the International Classification of Functioning, Disability, and Health (ICF) model which has gained momentum in the area of research in childhood disability.

## Development of the Conceptual Framework

### Theoretical Basis of the conceptual framework

Newborn hearing screening is the first step in a system of care encompassing hearing and communication development. The framework proposed in this paper builds on the International Classification of Functioning, Disability, and Health (ICF) model which has become widely acknowledged in the literature on disabilities since its introduction by the World Health Organization in 2001 (World Health Organization, 2001). The ICF model differs from previous models of disability in that it embraces a new paradigm where health and well-being are seen as an interaction between the individual and his/her environment. In this model, there are desired activities (outcomes) for the

individual which eventually lead to fuller participation in society. Applying the ICF model to infant hearing, outcomes can be conceptualized as consisting of communication outcomes for the child such as hearing, communication and social skills as well as process and quality of life outcomes for the family, all of which lead to fuller participation in everyday life. Drawing on this broader conception of health outcomes, these outcomes can be envisioned as a complex interplay between the hearing impairment, child characteristics, family characteristics and environmental or contextual factors, acting at the child, family and community level. Effectively, the ICF model is a framework that attempts to capture the notion of multiple outcomes and, consistent with a population health perspective, the model emphasizes contextual factors as contributing to the functional well-being of the individual. Contextual factors such as easy access to quality intervention services, family resources, as well as family and social supports may provide a better opportunity for positive outcomes from early hearing and communication development programs. The model recognizes that an intricate interaction of causal factors can shape the developmental outcomes in infant hearing loss. The ICF model represents a starting point for reflecting on the myriad of factors that interact with early confirmation of hearing loss through population-based screening to influence outcomes for children and families.

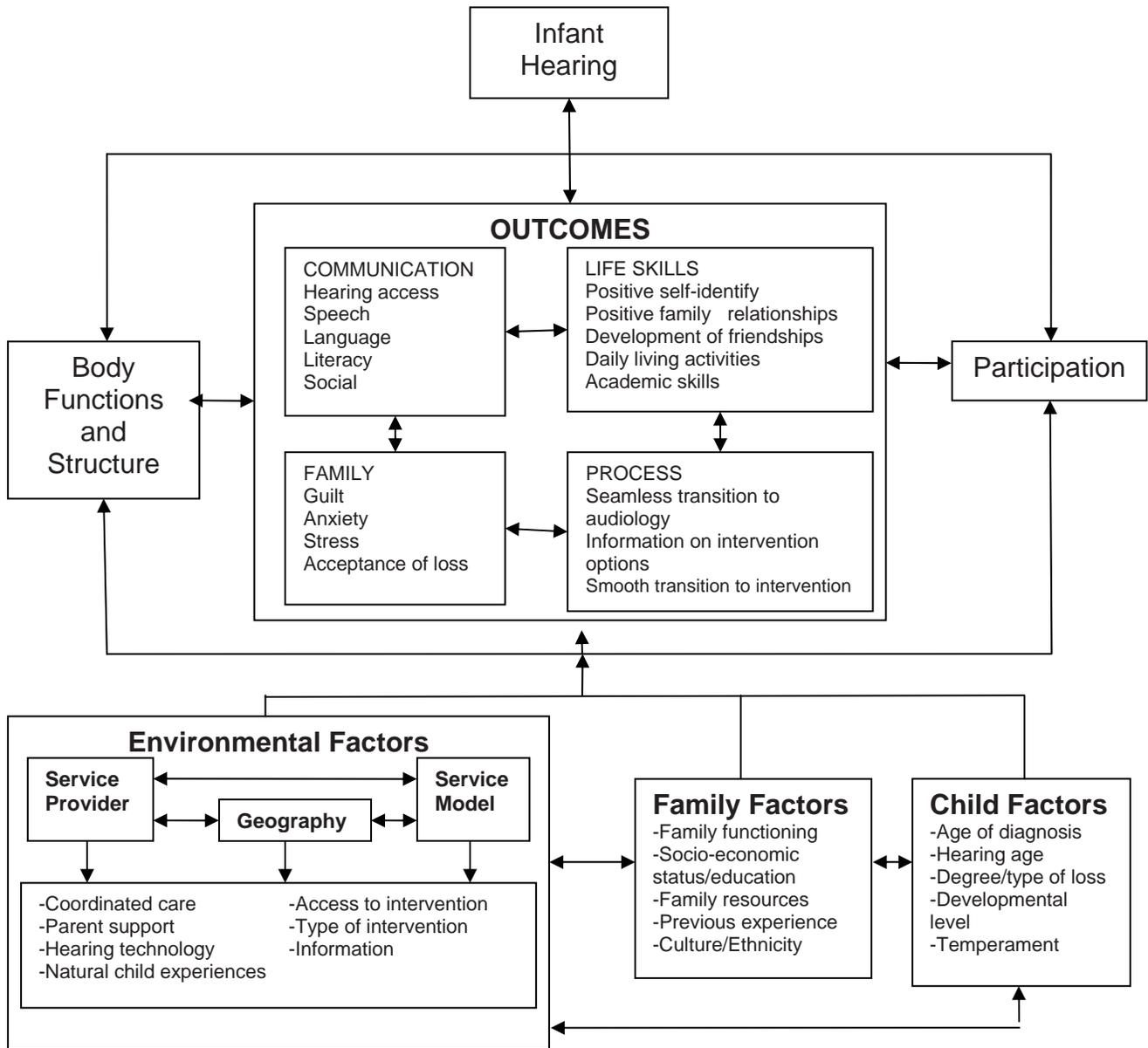
This ICF framework served to categorize the published literature and provided a reference for the subsequent research which motivated the development of the new framework. As noted, the proposed framework is informed both by the extant literature and a series of recent studies described above that examined broader outcomes and explored determinants of outcome beyond proximal factors. An important feature of this research is that it privileged the perspective of the parents who are so intricately involved in the care process.

### Revised conceptual framework for infant hearing

The new framework proposed in this paper furthers the understanding of infant hearing research in regard to the current focus on early identification. Figure 1 presents a conceptual view of how the new findings and the literature align with and extend the initial ICF framework which guided the research.

The ICF conceptual framework has been reconfigured to integrate and advance this new knowledge (Figure 1). The term "Infant Hearing" rather than hearing loss was selected as the title for the framework in accordance with the terminology adopted by the Canadian Working Group on Childhood Hearing. This task force was commissioned by the Government of Canada, to review evidence and develop a resource document on newborn hearing screening as the country embarked on population-based screening initiatives (Canadian Working Group on Childhood Hearing, 2005).

In the proposed framework, body functions and structures have been retained from the original ICF model and refer



**Figure 1:** Conceptual framework of outcomes and factors for infant hearing

to the physical/sensory and functional limitations of an individual's disability (World Health Organization, 2001). The outcomes are arranged and defined as four interrelated outcomes: communication outcomes, life skills outcomes, process outcomes, and impact on family outcomes. These categories were selected for presentation in the framework based on recent research which indicated that parents clearly viewed improved communication outcomes and related life skills as the primary reason for newborn screening, followed by benefits related to the process of identification of hearing loss (Fitzpatrick, Graham, et al., 2007). In the modified framework, each outcome category has been further defined to incorporate the findings of the research. The outcomes have been arranged to reflect that they are not discrete and separate phenomena but rather have the potential to interact with each other. For example, in this

research, families who perceived that their children had access to hearing (communication outcome) expected that their children would have positive life skills outcomes such as positive self-identity and family relationships. These families also described the positive impact of early identification of hearing loss on the family whereas some families who were concerned about their child's poor communication skills attributed it to late diagnosis and referred to the increased guilt and anxiety at the family level (Fitzpatrick, Graham, et al., 2007). Although knowing early was perceived as beneficial, families have also described the initial identification of hearing loss as a stressful period for them, (Fitzpatrick, Graham, et al., 2007; Tattersall & Young, 2006). Families who experienced difficulty with the referral process to audiology (process outcome) also associated this experience with increased stress, frustration,

and anxiety for the family and with reduced opportunities for the child to learn through hearing. Although access to services may not traditionally represent an outcome of NHS initiatives, this notion emerged as a powerful theme in parent interviews which led to its inclusion in the framework as a potential outcome (Fitzpatrick, Graham, et al., 2007). Taking the perspective of families, who obtain health care in a socialized medical system, the ease of access to services and subsequent early confirmation of hearing loss can be a useful outcome of screening programs. Delayed or inconsistent access was viewed as a barrier to necessary services, for example, hearing aids/cochlear implants and therapy which directly impact outcome. The definition of outcomes provided by this study attempts to extend the field beyond the narrow and more traditional boundaries common to previous investigations of the benefits of population screening.

The objective evidence for superior language outcomes from early intervention remains inconclusive. This is due to the difficulty in controlling for many other variables such as severity of hearing loss, technological advances in hearing devices, family involvement, type of intervention and type of service models. The findings of the research conducted for this framework and a considerable body of other literature points to the importance of a myriad of factors in influencing outcomes in children (Moeller, 2000; Vohr, Moore, & Tucker, 2002; Wake et al., 2005; Yoshinaga-Itano, 2003a) permit an elaboration of these factors in the framework. In this framework, these factors are classified as environmental factors, family factors, and child factors; they are positioned below the outcomes in accordance with the presentation format in the ICF model (World Health Organization, 2001). The boxes for environmental factors, family factors and child factors have been ordered from left to right as environmental factors appeared to most closely interact with family factors to facilitate or create barriers to meeting families' needs such as technology and intervention services. For example, families who described financial hardship which in turn interfered with timely access to hearing technology described a barrier that is directly influenced by family circumstances (Fitzpatrick et al., 2008). This factor has the potential to impact the child's access to hearing, and eventual outcomes in multiple domains. Second, in particular, the environmental factors box has been rearranged to include and reflect the findings of the study. In this reconfigured framework, service providers, geography and service models are seen as dynamic and interrelated factors that can influence and determine the availability of other components, e.g., hearing technology, access to service, availability of natural child experiences. In addition, coordination of care, parent support, and information access which emerged as strong themes in the qualitative interviews with families (and received high preference values in the conjoint analysis) have been added as characteristics of the environment (Fitzpatrick, Coyle, et al., 2007). Finally, in the category of child factors, hearing age (age at which child begins to hear sound) has been added in addition to age of diagnosis

to reflect this concept, which so strongly emerged in this research, both as a positive consequence of population screening (i.e., access to hearing) and as a contributor to outcome from the perspective of families. Although newborn hearing screening can lead to earlier "access to hearing," research has shown that even in countries with public health care systems, some children still experience delay to the fitting of amplification due to other medical concerns, severity of hearing loss or parental indecision (Durieux-Smith et al., 2008). In addition to child factors related directly to the hearing loss, other child characteristics such as developmental level (e.g., the presence of other disabilities) and temperament contribute to overall outcomes.

## Discussion

Population-based infant hearing screening has received worldwide attention as an opportunity to improve developmental outcomes for children with hearing loss. Early detection of hearing loss represents an opportunity for improved and perhaps even age appropriate communication outcomes for children when screening is embedded in a comprehensive system of care (Hyde, 2005; Joint Committee on Infant Hearing, 2007). Providing evidence of the effectiveness of NHS has proved to be daunting and potentially delays the adoption of screening initiatives in some regions. This paper extends the original ICF model to the field of infant hearing research. The modified framework is grounded in a population health perspective which shifts thinking from clinical treatment to determining how population health interventions can have the greatest impact on outcomes (Evans & Stoddart, 2003). A hallmark of a population health perspective is the acknowledgement of the complex and overlapping interactions among the various determinants of health. Applying a population health perspective, the proposed framework defines broader outcomes of early identification of childhood hearing loss from the perspective of families and highlights contextual factors such as access to parent support and coordinated services, which may be important determinants of outcome to consider in the evaluation of screening initiatives. This conception of infant hearing development is consistent with the comprehensive approach to newborn hearing screening and intervention practices supported by the Joint Committee on Infant Hearing (2007).

The synthesis of the findings into a new framework which encompasses multiple outcomes and a diversity of determinants of outcomes provides a common language for audiologists, language and other specialists, program administrators and policy makers interested in population infant hearing practice and research. Assembling the findings in the revised framework brings to light the fact that population infant hearing screening is not a single intervention but rather a catalyst for multiple interventions which potentially affect different levels of the system, including the individual (child), family, service provision and societal levels (Edwards et al., 2004). This further explains why it may be extremely difficult to isolate the effects of lower age of identification through screening

on longer-term communication outcomes as the implementation of universal screening programs have typically translated into multiple interventions at multiple levels of infant hearing care (Bamford et al., 2005; Hyde, 2005). Furthermore, as reflected in this framework, many of the factors (e.g. hearing technology, type of intervention) can be viewed as layered or “nested” within other determinants such as the service model of care (Edwards et al., 2004). Interventions such as universal screening can effectively create synergies which can optimize the impact of screening and ultimately affect the ability of children and families to more fully participate in society.

The purpose of this paper is to present a framework that outlines multiple outcomes and factors which can be used as a guide for future research. The development of a single research design which would incorporate these components was not the intent of the research and is beyond the scope of this project. Yoshinaga-Itano (2004) provides a comprehensive summary of the challenges and limitations of conducting the kind of research that is required to reach the highest levels of scientific evidence. As pointed out by the author, such a research design may be impossible to achieve in this field due to our current inability to reliably measure some of the more complex variables such as parental involvement, and the contribution of other contextual factors. As a first step, this framework attempts to acknowledge and systematically organize the intervening variables. Multiple types of research paradigms using both quantitative and qualitative research methods may help structure and refine future research questions and measures. Despite these limitations, it is hoped that the proposed framework can act as a reflective framework for research and practice.

Although the proposed framework was conceptualized based on the extant literature, it was also largely informed by recent work undertaken in one Canadian province where there is a focus on oral communication development following early identification of hearing loss. Moreover, this research was conducted in the context of publicly funded medical care which translates to challenges in accessing some health services, and therefore certain elements may not be applicable to all settings. Although some of the constructs put forward may be context or region-specific, the framework serves to unite some of the determinants of outcome in child hearing research. Overall, the framework is advanced to stimulate and shape thinking as new evidence is collected in the field of infant hearing, evidence which will serve to fill current gaps in this framework.

In summary, as a population health intervention, infant hearing screening has thrust childhood hearing loss under the public health lens. This visibility brings with it a responsibility to ensure that decisions related to hearing screening and subsequent management of the disorder are grounded in the best available evidence. This framework was developed to contribute to science by offering insights into measurable outcomes, as well as the perceived benefits, needs and values of those who use and are most affected by population-based infant hearing screening. Increasingly,

there is a realization that infant hearing screening cannot be isolated from the subsequent management of hearing loss and family supports. The framework lays the foundation for research on NHS and offers a format to conceptualize questions for the next generation of research. It is hoped that this framework can inform the development, implementation and evaluation of population hearing screening programs as they continue to grow.

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