

The Need and Uses of the Ida 'My World' Counselling Tool in Paediatric Rehabilitation for Hearing-impaired Children

by

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ABSTRACT

This paper reports on the needs and uses of the Ida 'My World' counselling tool in paediatric rehabilitation for hearing-impaired children. The 'My World' tool was developed by the Ida Institute, Denmark, and depicts three different environments: a classroom, a home, and an outdoors area. The child can place moveable figures and everyday objects in the various environments to describe their communication successes and challenges in their everyday life. The study explored finding out whether this tool is needed in various professional clinics, from both the child and professional perspectives in both questionnaire and interview formats. This included finding out from hearingimpaired children, teenagers and young adults whether they felt adequately prepared to manage their hearing loss at home, at school and in social situations; what it is that they felt they needed from the service, and whether they thought the tool might help children to explore the issues that arose in daily life with professionals. It also included finding out from professionals (audiologists, Teachers of the Deaf and psychologists) if they felt that they had a good understanding of hearing loss from the child's perspective, or if this was perceived as a 'gap' in their understanding, and what additional skills or resources they felt might enhance the use of the tool. The study also included documenting professionals' reactions to the tool, determining what age of child would respond well to this tool, and to find out what uses they could envisage for the tool. There were seven parts to this study and 28 participants - 17 audiologists, 3 psychologists and 3 Teachers of the Deaf, and 5 hearing-impaired participants (2 children, 2 teenagers, and 1 young adult). It was found that the majority of professionals felt that there was a gap between the counselling by an audiologist and a psychologist provided to hearing-impaired children, and also a gap in their understanding of hearing loss from the child's perspective. The comments from both the professionals and the hearing-impaired participants highlighted that there was a need for the tool. The majority of professionals felt that the tool would allow them to obtain both the child's perspective of their hearing loss and help the child, and that the tool would improve and enhance the outcomes of paediatric rehabilitation. Overall the participants felt the tool had the potential for a more holistic usage by many professionals, including audiologists, Teachers of the Deaf, psychologists, speech therapists, occupational therapists and counsellors. The dominant age range chosen for the tool was 5-12 year olds, but potentially to late teens if adapted for different ages. Of the hearing-impaired subjects' perspectives, they suggested that there needed to be more counselling on hearing strategies by all professionals, particularly in relation to self-advocacy and self-efficacy, that there was a need for this tool for hearing-impaired children, and that communication strategies are what they feel is most needed from the service. It is argued here that there is a need for the 'My World' tool from both professional and hearing-impaired perspectives and that defined uses can and need to be formally established for each professional, and that that counselling on hearing strategies is an area in audiology that needs to be improved for paediatric rehabilitation. The present study highlights the importance of giving the child a voice to actively participate in their rehabilitation.

Key words: 'My World', Ida Institute, child's perspective, paediatric rehabilitation, self-advocacy

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DECLARATION

I declare that this thesis is my own account of my research project and contains as its main content work which has not previously been submitted for a degree at any tertiary educational institution.

HRound

Jessica Louise Round

1. Introduction

Because of their reduced vocabulary and communication skills, a child with a severe hearing loss can be at a great disadvantage in explaining to parents, teachers and professionals the problems they face day to day. The 'My World' tool was developed by the Ida Institute, Denmark, and is a tool which can be used during a consultation session by a professional to incorporate the child's perspective of their hearing loss, giving them a voice and making them an active participant in their rehabilitation process (Gregory, Parfitt, & Nielsen, 2012; Ida Institute, 2012). Thus, the 'My World' tool can help facilitate an understanding of hearing loss from the child's point of view. The tool can facilitate open-ended questionning and provides a way to stimulate curiosity and shared understanding about aspects of communication relevant to the child (Ida Institute, 2012).

The tool consists of three different environments: a classroom, a home, and an outdoors area, as shown in Figure 1. The child can place moveable figures and everyday objects, as shown in Figure 2, in the various environments to describe their communication successes and challenges in their everyday life (Ida Institute, 2012).

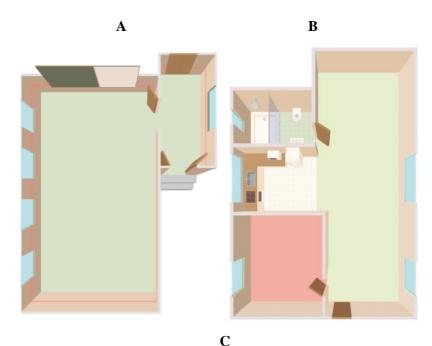




Figure 1. The three different environmental boards of the Ida 'My World' tool, A: The classroom; B: The home; and C: the outdoors (Ida Institute, 2012).

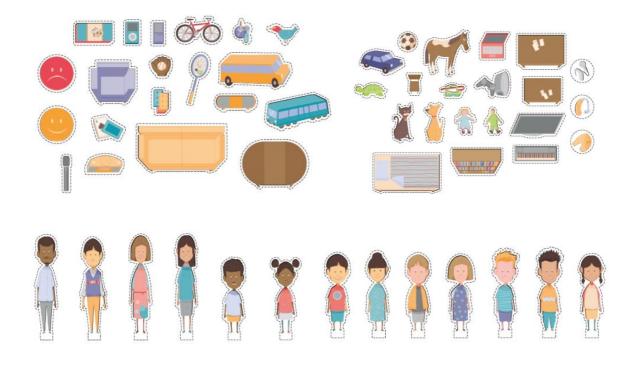


Figure 2. The moveable figures and everyday objects that the child can move around the different environment boards – the home, the classroom and the outdoors in the Ida 'My World' tool (Ida Institute, 2012).

The Ida Institute has described a way in which to use the tool, and has also provided a video-based user guide on the Ida website (<u>www.idainstitute.com/myworld</u>) (Ida Institute, 2012). They suggest three phases to using the tool:

<u>Phase 1: Choosing the environment and being curious</u>. This is where the professional chooses the environment most relevant to the child in the appointment, and they ask the child to make it their own by selecting items that are meaningful to them in their daily life. The professional can ask openended questions and listen to the child's responses. This may begin by asking the child to give the professional a tour of the environment (Ida Institute, 2012).

<u>Phase 2: Understanding successes and challenges and identifying strategies</u>. This is where, based on the descriptions given by the child, the professional can identify the child's current communication strategies. Those that work well may be reinforced by the professional, and those which the child describes as challenging, can be discussed with the child about possible new strategies which could result in more easy communication (Ida Institute, 2012).

<u>Phase 3: Documenting decisions and strategies</u>. This phase is where the professional can use the documentation form, as shown in Figure 3, to record what was learned about the child's communication, and the goals and actions agreed upon (Ida Institute, 2012).

There is also a 'My World' listening guide, as shown in Figure 4, which can help the professional listen actively to what the child is saying (Ida Institute, 2012).

MY WORLD	
SESSION	
DOCUMENTATION FORM	
Based on the way the child has created their home / classroom and told their story of daily life:	
1. What did you learn about the child?	
2. How does the child manage communication at: School Home Other	
 Provide some examples of effective strategies used and some challenges to be addressed. Strategies: Challenges: 	
4. What goals did you agree upon?	
Idainstitute	
5. How could others help achieve these goals?	•••
 5. How could others help achieve these goals? 6. What action has been agreed for: <i>The child</i> 	••••
6. What action has been agreed for:	••••
ó. What action has been agreed for: <i>The child</i>	••••
6. What action has been agreed for: <i>The child</i> <i>The parent</i>	••••
6. What action has been agreed for: The child The parent The teacher	••••
6. What action has been agreed for: The child The parent The teacher The audiologist	••••
 6. What action has been agreed for: The child The parent The teacher The audiologist 7. What did you learn that you did not know before? 	••••
 6. What action has been agreed for: The child The parent The teacher The audiologist 7. What did you learn that you did not know before? 	••••

Figure 3. Session documentation form when using the Ida 'My World' tool with hearing-impaired children (Ida Institute, 2012).





Figure 4. The 'My World' tool listening guide, which can be used when actively listening to what the hearing-impaired child is saying (Ida Institute, 2012).

1.1. Development of the Ida 'My World' tool

The Ida 'My World' tool was developed from an Ida Institute paediatric forum discussion which included a focus group of about twenty paediatric audiologists from America and the United Kingdom, who investigated and explored how Ida tools could be applied to paediatric programs. (Gregory et al., 2012). The starting point for the focus group was two questions:

1) What are the unique challenges facing professionals who work with children with hearing loss and their families?

2) How can existing Ida tools be adapted or improved to address some of these challenges?

The group focused on specific factors when talking through their ideas, including: considering the child's life experience and sphere of activity (not just educational issues); focusing on enabling the child to make a first-hand contribution; putting real value on the interaction/conversation; promoting an evaluative approach; not being prescriptive, and most importantly, child-centred communication (Gregory et al., 2012). They brainstormed in this focus group and came up with many ideas, and out of this creative collaboration emerged a new audiological tool. Participants came up with the idea of creating figures representing themselves, and those things that are significant to them in different

environments to enable the child to express what happens in the most important everyday environments such as home or at school and to describe what happens from a social and communication point of view in these situations (Gregory et al., 2012). The focus group tool draft is shown in Figure 5. The result is a story provided from the child's point of view which is multifaceted:

 \mathbf{C} – <u>Communication</u>: what are the communication challenges and success in these environments?

A - Affect: how does the child feel about communication and relationships in these environments?

 \mathbf{R} – <u>Reception and Expression</u>: how effectively is the child using language and understanding it, one can gain a rich language sample

 ${f S}$ - <u>Self:</u> from these stories the audiologist can gain information about the child's sense of self

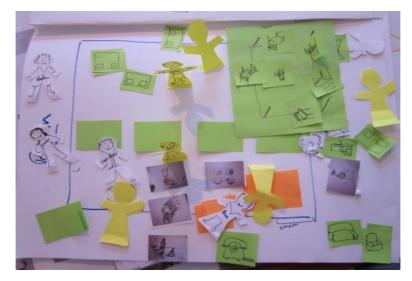


Figure 5. Focus group tool draft, depicting the use of figures to represent the child and the people who are important to them, in important everyday environments (Gregory et al., 2012).

Secondly, the tool was presented to a workshop in London to explore the tool prototypes and to create a more refined version of the tool, as shown in Figure 6.

The nine underlying principles in the tool prototype were:

- 1) enable a patient-centred dialogue
- 2) provide a supportive environment for children to tell their own experience
- 3) joint focus and attention on what is relevant to the child
- 4) discussion led by the family and child, related to their reality
- 5) externalise issues related to hearing loss
- 6) provide an insight into positive experiences and challenges faced by the child and family
- 7) enable audiologists to hear details not usually obtained
- 8) enable joint goal setting
- 9) engaging and motivating

The tool was then field-trialled by audiologists that were involved in its conception, as shown in Figure 6. From this, the tool was taken to a Danish design company, and the tool was refined and scaled down into the final version for production (Gregory et al., 2012).

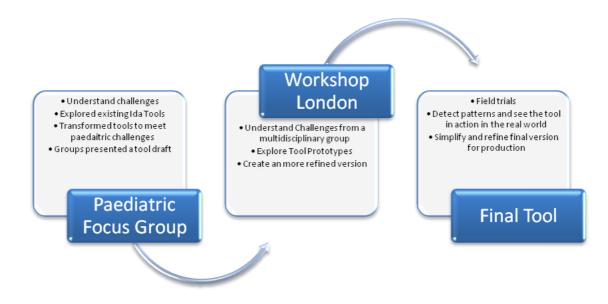


Figure 6. Development process of the Ida 'My World' tool. There were three main steps which included a paediatric focus group, where an understanding of the challenges experienced by paediatric audiologists was created and the exploration of possible solutions in the form of "tool proposals", a workshop in London, which explored tool prototypes, and the final tool production after field trials, and the tool's simplification and refinement (Gregory et al., 2012).

1.2. Family vs. Child Centred Care

In paediatric audiology, following work from many such as Luterman, the focus is on familycentred care, and this is essentially the basis for paediatric rehabilitation (Kovacsa, Bellinb, & Fauria, 2006). Family-centred care recognises that each family is unique, that the family is a constant in the child's life, and that the family are most often the experts on the child's abilities and needs. Thus, the family works with the professional to make informed decisions about the services and support the child and family receive (Kovacsa et al., 2006). In adult rehabilitation, we know that patient-centred care leads to optimal outcomes for the adult. This approach was developed from the work of Carl Rogers, a psychologist, in the 1940s and 1950s (Kirschenbaum, 2004). The approach is "nondirective" and aims to provide patients with developing a sense of self, while the clinician creates a psychological atmosphere to permit this (Kirschenbaum, 2004). This is so that the client can realise how their behaviour, attitudes, and feelings are being affected (Kirschenbaum, 2004). It is achieved by the clinician displaying congruence, unconditional positive regard, and empathy by relying exclusively on accepting the client for who they are, and carefully listening to what they have to say (Cepeda & Davenport, 2006; Kirschenbaum, 2004). This creates a basis for further understanding of the client's experience, and allows the clinician to lead positive actions in the client through their selfactualisation (Kirschenbaum, 2004).

A major question for paediatric audiology is when to transition from family-centred care to patient-centred care (putting the needs of the child first), or is it possible for the two to be compatible? Is an earlier transition desirable, and what/how could a rehabilitation tool facilitate such a transition?

1.3. Narrative therapy

'Narratives' are an element of human communication, which is a means to understand and organise our experiences, and which we use to construct self-identities (*Digital Interactive Narrative Tools for Facilitating Communication with Children During Counseling: A Case for Audiology*, 2012). Narrative therapy emphasises that it is the experiences of one's story that serve as a means to unfolding alternative, more purposeful stories of one's life (*Digital Interactive Narrative Tools for Facilitating Communication with Children During Counseling: A Case for Audiology*, 2012). Thus, therapy becomes a practice that promotes conversations through narratives, to engage in a process which consists of storying and re-storying one's life and experiences, gradually moving from

problem-saturated stories of one's life, and towards therapeutic change (*Digital Interactive Narrative Tools for Facilitating Communication with Children During Counseling: A Case for Audiology*, 2012). Using this approach when counselling children allows maintenance of the centrality of the child through narrative conversations of children's individual stories, rather than focusing on the representations given by teachers, professionals, or parents/guardians (*Digital Interactive Narrative Tools for Facilitating Communication with Children During Counseling: A Case for Audiology*, 2012).

Narrative therapy is historically linked to the work of Gregory Bateson (1972, 1980), who posited that people have "world maps" that establish rules for the selection of information about perceived objects or events. The presuppositions, premises and expectations that create these world maps also contribute to sensory limitations in the individual. Our beliefs and assumptions influence how we see differences and draw distinctions between certain events (Furlonger, 1999). The therapist uses questions to investigate the problem, and makes it clear that he or she is constantly seeking an ongoing understanding of the client's experience. The therapist is careful not to dismiss the client's own knowledge and abilities by assuming the role of the expert, and so uses "curious" questions in an attempt to guard against this role (Furlonger, 1999).

In narrative therapy, some of the first questions children can be asked are what are called "landscape of action" questions (Furlonger, 1999). These are used to focus on both the recent and the more distant history, and thus plot the development of the problem. Such questions can help children reach back in time and identify landscapes different from the "problem saturated" stories that dominate their present lives. The child can be asked further questions about his or her knowledge of the problem and what his or her abilities are in relation to it (Furlonger, 1999). "Landscape of consciousness" questions follow, which take the form of asking children to articulate preferences, desires, personal qualities, beliefs, and intentions toward the problem and encouraging them to "revision" what they will do in relation to the problem. Following this, "experience of experience" questions are used, whereby the therapist encourages the child to imagine what another person's experience of him or her could be, and so it becomes possible to ask the child to reach into his or her experience and consider alternative experiences. "Experience of experience" questions focus on future developments, within landscape of action and landscape of consciousness questions (Furlonger, 1999). Evidence about the use of narrative therapy with children who are deaf or hard-of-hearing is largely anecdotal (Furlonger, 1999).

Digital Interactive Narrative Tools for Facilitating Communication with Children During Counseling: A Case for Audiology (2012) has discussed the application of narrative therapy to the 'My World' tool. They used an adaptation of the scaffolding conversations map, where specific modifications relevant for audiology counselling were made, while maintaining the philosophy of the original structure. The developed step-by-step guide provides six steps: 1) identify the problem, 2) model the world, 3) explore the problem, 4) reflect on the problem, 5) explore strategies, and 6) form strategies. These help the counsellor to move through the 'problem externalisation process', both structuring the conversations with the child, and leading the child's use of the application (Digital Interactive Narrative Tools for Facilitating Communication with Children During Counseling: A Case for Audiology, 2012).

1.4. Play therapy and interactive storytelling

Play therapy has been accepted as a developmentally appropriate intervention for children experiencing a broad range of problems since the ground-breaking work of Virginia Axline in the 1940s. However, play therapy has long been criticised for a lack of adequate research to prove its efficacy (Bratton, Ray, Rhine, & Jones, 2001). Play therapy is the systematic use of a theoretical model to establish an interpersonal process wherein trained play therapists use the therapeutic powers of play to help clients prevent or resolve psychosocial difficulties, and achieve optimal growth and development (Bratton et al., 2001). Central to Axline (1964)approach to play therapy (1964) was the

position that the primary focus of the play therapist should be *being with* the child, rather than *doing for* or *doing to* the child. Play has been linked to problem-solving, coping skills, and creative thinking, as well as the development of language (Johnson, Christie, & Yawkey, 1987). In play therapy, play is viewed as the vehicle for communication between the child and the therapist, whereby the child will use play materials to directly or symbolically act out feelings, thoughts, and experiences that they are not able to meaningfully express through words (Axline, 1964; Smith, 2002).

While observing hearing-impaired children in a play therapy setting, Sisco, Kranz, Lund, and Scwartz (1979), found that their play resembled that of hearing children two to four years younger. They speculate that, while hearing-impaired children move through the same normal developmental sequences of play as their hearing peers, they do so at a slower pace, because of their developmental language delays (Sisco et al., 1979). In the free play of hearing-impaired youngsters, they are less able to engage in dramatic play activities than normal-hearing children, and hearing-impaired youngsters spend significantly more time in constructive play than in adventurous games that suggest fantasy or imagination, such as cops and robbers, pirates, etc. (Casby & McCormack, 1985).

Play therapy, while it is not a solution to all of a child's problems, is one method used to help children with disabilities develop a sense of strength and competency (Carmichael, 1993). Play therapy literature concerning children with disabilities is divided into two distinct approaches. The first approach primarily emphasises the emotional adjustment, or the 'I am'. The 'I am' attribute is usually provided by counsellors, psychologists, mental health nurses, social workers, or other mental health providers. The second approach primarily emphasises physical activity or the 'I can' (Carmichael, 1993). Through play, the child explores the 'I am' and the 'I can' characteristics of personality development. The 'I can' attribute is related to feelings of competence and control of circumstances. The 'I am' attribute helps the child develop positive self-esteem, personal competency, and self-reliance in relation to specific circumstances (Carmichael, 1993). Such therapy can be conducted using directive play which includes specific activities that are aimed at developing selfesteem, personal competency, and self-reliance. (Carmichael, 1993). Bradtke, Kirkpatrick, and Rosenblatt (1972) recommended intensive play for children with physical and sensory impairments. The purposes of intensive play are (a) to build awareness of self, others, and environment; (b) to reduce fear of physical contact; and (c) to help the unresponsive child become responsive (Carmichael, 1993). Play therapy thus provides the child with experiences that can help the child define "who I am" and "what I can do". In such an environment, the child is nurtured to grow strong and independent, with realistic goals and aspirations (Carmichael, 1993).

Narrative and play therapies are generally comprehended as two separate approaches, however, if applied collaboratively, it is suggested that they could provide effective means of communication with children, to help overcome the prevalent communication gap, whilst being able to offer children more appropriate means of communication (*Digital Interactive Narrative Tools for Facilitating Communication with Children During Counseling: A Case for Audiology*, 2012).

1.5. Stages of psychosocial development of children and the psychosocial features of hearingimpaired children

The works of Erikson proposed that there are stages of psychosocial development which characterises an individual as they advance through the eight life stages, as one negotiates his or her biological forces and socio-cultural forces (Schlesinger, 1978). Each stage is characterised by a psychosocial crisis of two conflicting sources, as shown in Table 1, which depicts the childhood/young adult's spectrum of the stages (stages 2-5).

Approximate Age	Virtues	Psycho Social Crisis	Significant Relationship	Existential Question	Examples
2-4 years	Will	Autonomy vs. Shame and Doubt	Parents	Is It Ok To Be Me?	Toilet Training, Clothing Themselves
4-5 years	Purpose	Initiative vs. Guilt	Family	Is It Ok For Me To Do, Move and Act?	Exploring, Using Tools or Making Art
5-12 years	Competence	Industry vs. Inferiority	Neighbours, School	Can I Make It In The World Of People And Things?	School, Sports
13-19 years	Fidelity	Identity vs. Role Confusion	Peers, Role Model	Who Am I? What Can I Be?	Social Relationships

Table 1. The four main stages of psychosocial development of childhood and teenage-hood showing the approximate ages, virtues, psychosocial crisis, significant relationship, existential question and examples (Schlesinger, 1978).

Stage two navigates the psychosocial crisis of autonomy vs. shame and doubt. Here the child asks themselves "Can I do things myself?" or "Must I rely on others?" It is also where the child, if denied autonomy, will turn against their urges to manipulate and discriminate, and shame develops with the child's self-consciousness. The sense of autonomy fostered in the child, and modified as life progresses, serves the preservation in economic and political life of a sense of justice (Schlesinger, 1978). Stage three is *initiative* vs. guilt, and is where the child asks themselves whether they are good or bad. They have judgement of feelings, and ability to complete tasks. Initiative adds to autonomy the quality of undertaking, planning, and attacking a task for the sake of being active and on the move. The child feels guilt over the goals contemplated and the acts initiated, in exuberant enjoyment of new locomotor and mental powers (Schlesinger, 1978). Stage four is *industry* vs. *inferiority*, and is where the child asks themselves "am I successful or worthless?" and they obtain the ability to meet adults' expectation for more complex skills - competence/perseverance/self-consciousness (Schlesinger, 1978). That the child can bring a productive situation to completion is an aim which gradually supersedes the whims and wishes of play. The fundamentals of technology are developed in this stage (Schlesinger, 1978). Stage five is *identity* vs. role confusion, where the adolescent asks themselves, "who am I and where am I going?". Here the aim is to reconcile 'who I am' and 'what society wants me to be'. The adolescent is newly concerned with how they appear to others, and 'ego identity' is the accrued confidence that the inner sameness and continuity prepared in the past are matched by the sameness and continuity of one's meaning for others, as evidenced in the promise of a career (Schlesinger, 1978). In this stage the individual finds the inability to settle on a school or occupational identity disturbing (Schlesinger, 1978).

Jean Piaget, a Swiss developmental psychologist, between 1926-1952 published work on his theory of intellectual and perceptual development (Dinkmeyer, 1965). His theory was that all adaptive behaviour could be understood in terms of its organisation as a total system (holism), whereby two processes are vital for development: assimilation, in which the child incorporates new elements into their existing structure; and accommodation, in which the structure itself adjusts to new elements (Dinkmeyer, 1965). Thus, the child is viewed as an ever organised entity who accommodates itself to external reality (Dinkmeyer, 1965). Piaget's theory further defined a period of preparation for an organisation of concrete operations (2-11 years), in which the child's representational thought first emerged. Representational thought has a symbolic capacity, and is free from the limits of concrete reality (Dinkmeyer, 1965). This period is followed by a period of formal operations (11-15 years), whereby representational thought becomes oriented towards reality (Dinkmeyer, 1965). Thus, Piaget's theory provides guidelines and limitations in the area of cognitive development.

Psychosocial difficulties involve both social and psychological aspects of a child's life, referring to the interrelation of behavioural and social factors (Dammeyer, 2010). A child without psychosocial difficulties is characterised, for example, by feeling good about oneself, feeling comfortable around

other people, controlling anxiety or tension, and being able to meet their goals (Dammeyer, 2010). The psychosocial concept is related to quality of life and general well-being.

There is no consensus about the incidence of psychosocial difficulties among children with hearing loss, however studies have indicated that the prevalence ranges from 20% to 50% (Dammeyer, 2010). Many researchers have documented significantly higher occurrences of behavioral and emotional problems among deaf and hard-of-hearing children when comparing hearing and non-hearing school children (Smith, 2002). Bat-Chava (1994) reviewed 22 studies comparing the self-esteem of hearing and non-hearing children, and determined four factors contributing to the self-esteem of deaf people. These included the family environment, hearing status (degree of hearing impairment), school and educational environment, and group identification (Bat-Chava, 1994). The review revealed that, of these, perhaps the most essential element in the early family and school environment that affects the deaf and hard-of-hearing child's self-esteem, was the quality of the parent(s)' and teacher's emotional connection with the deaf child (Bat-Chava, 1994).

Some studies have suggested that there is a lower level of psychosocial difficulty among children attending mainstream schools compared to special schools, and lower among deaf schools compared to hearing-impaired units (Dammeyer, 2010). A higher prevalence of psychosocial difficulties among boys has also been found in some research by Polat (2003) and Sinkkonen (1994) (Dammeyer, 2010). There have been contrasting studies about the age range of higher prevalence of psychosocial difficulties, with one study by van Eldik et al. (2004) finding a higher prevalence among deaf children 12-18 years old than that of 4-11 years old, whereas Polat (2004) found that older children were better adjusted than younger children (Dammeyer, 2010). Interestingly, many of these studies were conducted with questionnaires for the parents or teacher of the children, rather than for the children themselves (Dammeyer, 2010).

The literature also suggests that deaf children who are born to deaf parents tend to have higher self-esteem than deaf children who are born to hearing parents (Smith, 2002). Luterman (1999) suggests that parental attitude related to the child's hearing loss is a key element regarding the emotional effects of hearing loss on the child. This means that how the parent responds to the child's deafness greatly affects how the child comes to feel about his or her deafness or hearing difficulty (Luterman, 1999). Luterman (1999) also suggested that the young child who was born with hearing-impairment may experience no sense of loss, because it is impossible to lose that which one never experienced. Thus, he has argued, some hearing-impaired individuals come to view their deafness not as a pathological loss, but as a cultural deficit.

It is of important note that on entering preschool or primary school, especially in a mainstream setting, the child can become acutely aware of his or her differences, and experience painful isolation and depression, consequently developing a negative self-image (Luterman, 1999). Because deaf and hard-of-hearing children experience greater difficulty than their hearing counterparts in communicating their needs, wants, thoughts, desires, and feelings, they are likely to have lower self-esteem and less ability to show empathy to others than their hearing counterparts. In addition, they experience higher incidences of depression, estrangement, aggression, anger, frustration, and impulsivity (Luterman, 1999; Mason & Mason, 2007; Smith, 2002). Negative influences of hearing-impaired children on social participation and personal development (e.g. self-esteem, self-advocacy) may have lasting consequences for an individual's interpersonal relationships and perceived quality of life (Moeller, 2007). For example, Davis, Elfenbein, Schum, and Bentler (1986) have found a higher incidence of peer-acceptance concerns among school-aged children with hearing-impairment, compared to peers with normal hearing. Their study concluded that social problems "may constitute a major reflection of the effects of hearing-impairment, and society's attitude toward it, on children's development" (Davis et al., 1986).

If hearing loss in childhood affects academic and social abilities, influences on self-concept may be expected (Davis et al., 1986; Moeller, 2007). Self-concept or self-esteem is defined as a stable set of attitudes about the self, including a description and an evaluation of one's attributes and behaviours

(Moeller, 2007). A healthy self-concept must include some degree of self-confidence, and changes in self-concept depend on the experiences the child is exposed to, and the relative amount of opportunity for failure and success (Dinkmeyer, 1965). During the early school years, the child sees themselves through the eyes of their peers, and so their self-concept is directly affected by their attitudes (Dinkmeyer, 1965). There is a potent desire to be accepted as a participating member of a group, and so it is a painful experience for any child to feel inferior or unacceptable. These feelings can have a negative effect on the formation of self-concept (Dinkmeyer, 1965). Israelite, Ower, and Goldstein (2002) explored identity formation in a qualitative study of seven mainstreamed high school students with hearing-impairment (five moderately-severe, one severe, one profound). They found that most of the individuals perceived that they lacked knowledge of subtle social rules for communication with normal hearing peers, and this was described as a barrier to "fitting in" (Israelite et al., 2002). Negative experiences with teachers, including discrimination or being singled out because of hearing-impairment, were also reported. Closeness with peers who also had hearingimpairment was also found to play an important role in emotional well-being, and with experiencing a sense of belonging (Israelite et al., 2002). Moreover, significantly more children with hearingimpairment (30%) compared to normal hearing peers (5%) were rejected by their peers (Israelite et al., 2002).

1.6 Application to audiology and significance of this study

The significance of this study was to find out whether this tool is needed in various professional clinics, from the child and professional perspectives. This study also hoped to give the tool a more defined structure in regards to its use, to explore possible uses that had and had not yet been investigated, and investigated whether narrative and play techniques could potentially be applied to the tool. This could potentially lead to the tool's integration in the everyday clinical setting, which could help many hearing-impaired children worldwide in terms of their psychosocial development.

1.7 Research Objectives

The overall objectives of this research were to investigate whether there was a need for the 'My World' tool clinically, and to find out specific uses for the tool, with respect to hearing-impaired children. Specifically, this study investigated nine questions:

- 1) Does the counselling provided by the audiology, educational and psychology services adequately prepare a child to manage/live well with hearing loss at home, in school and in social situations?
- 2) Is there a need for this tool in paediatric hearing rehabilitation? Are there issues that are not addressed with current clinical methods?
- 3) Will this tool enable the audiologist to explore communication challenges and successes with a young child?
- 4) Could this tool enable the audiologist to explore with the child, environmental and personal adaptations that can reduce the burden of hearing loss on his or her everyday life?
- 5) Would this enhance/improve the outcomes of paediatric rehabilitation?
- 6) Are audiologists comfortable with working with this tool, or do they envisage challenges? What are those challenges?
- 7) Is there a way to help audiologists to incorporate this tool in the clinical setting?
- 8) Can this tool be used by paediatric psychologists to counsel the hearing impaired child? Is there a use for this tool in the clinical setting?
- 9) Can this tool enable audiologists, teachers of the Deaf/visiting teachers or psychologists fill gaps in the support of the hearing-impaired child?

To address the above nine questions, the specific aims of this research were:

- 1) to find out from hearing impaired children/young adults if they felt adequately prepared to manage their hearing loss at home, at school and with their friends, in terms of:
 - a. having a healthy self-esteem and self-concept;
 - b. fully understanding the benefits and limitations of amplification in their own personal lives;
 - c. feeling able to formulate strategies for dealing with difficult communication situations;
 - d. feeling able to self-advocate (good self-efficacy);
 - e. confidently asking for accommodations (self-advocating);
 - f. communicating well in difficult situations.
- 2) to find out from hearing impaired young adults/children what it is that they felt they need from the service.
- 3) to find out from hearing impaired children/young adults if and how they thought the Ida 'My World' tool might help children to explore the issues that arise in daily life with professionals.
- 4) to find out from professionals in the field, i.e. psychologists, audiologists and teachers of the deaf:
 - a. If they felt that they had a good understanding of hearing loss from the child's perspective or if this was perceived as a 'gap'.
 - b. If they felt that counselling hearing impaired children is or should be within their scope of practice.
 - c. If they felt comfortable with a counselling role in the rehabilitation of hearing impaired children.
 - d. How they might deliver counselling that is within the limits of their expertise.
 - e. What additional skills or resources they felt might enhance that role.
- 5) to document professionals' reactions to the Ida 'My World' tool and to find out what uses they could envisage for the tool in daily practice.
- 6) to determine approximately what age of child would respond well to this tool/to assist hearing impaired children in different psychosocial stages of development, perhaps used with multiple age groups?
- 7) to explore uses for this tool clinically that had and had not yet been explored.....
 - a. use child's own photos with the tool to engage them in scenarios of communication at home, school, or outdoors;
 - b. filial therapy (audiologists/psychologists teach parents to use play therapy between clinical visits);
 - c. gain an understanding of hearing loss from the child's perspective;
 - d. explore communication successes and challenges with friends and family;
 - e. identify child-centred communication goals that are meaningful and important to the child;
 - f. find out the strengths and resources the child has that we can build on and grow-solution-focussed therapy;
 - g. collaboratively plan intervention strategies that the child can and will implement to improve communication in social situations;
 - h. engage the child in shared decision-making e.g. exploring the effectiveness of amplification use in different situations, giving the child independence, understanding and control of their hearing aids;
 - i. externalisation of hearing loss;
 - j. re-authoring of the child's narrative;
 - k. communication with children who have very limited language.

1.8 Predicted Outcomes

By presenting the 'My World' tool to professionals such as audiologist, psychologists and Teachers of the Deaf/Visiting Teachers, it was predicted that their opinions on whether they could see some uses for this tool clinically and whether they thought such a tool was needed would be obtained. This would also highlight whether there was a gap between the boundaries of which these professionals support hearing-impaired children. By interviewing young children, teenagers and young adults their perspective of whether there was a need for this tool in helping the hearing impaired child would be obtained. Overall, the predicted outcome was that by using the 'My World' Tool, the professional would be able to give a more holistic rehabilitation program to the child and their family.

1.9 Hypotheses

- 1) There is a gap between the boundaries of the roles in which audiologists and psychologists play in the rehabilitation and support of hearing-impaired children.
- 2) There is a need for the 'My World' Tool to bridge this gap to make the boundaries ideally overlap to holistically support the hearing-impaired child in terms of their self-advocacy, self-concept, and development of strategies for dealing with difficult communication strategies.
- 3) Professionals using this tool will effectively gain the child's perspective of hearing loss.
- 4) There are many clinical uses for this tool by professionals.

2. Research Methodology

A qualitative and questionnaire-based research method was used, with 28 participants, including 23 professionals, and 5 hearing-impaired participants. The focus of this study was to obtain the professional opinions of audiologists, psychologists and Teachers of the Deaf and the perspectives and insights of hearing-impaired children, teenagers and young adults on this paediatric rehabilitation tool, and to uncover whether there was a need for this tool, and to define more specific uses for the tool. To be included in this study, hearing-impaired participants had a bilateral moderate to profound ranging sensorineural hearing loss, and were either being bilateral hearing aid users, or bimodal.

2.1 Part 1. Oticon Paediatric Conference in New Jersey, USA (19-21st October 2012)

This conference focused on patient-centred communication, and involved my supervisor, Karen Parfitt, and a Senior Ida Institute Audiologist, Melanie Gregory, discussing the use of the 'My World' tool with a group of American paediatric audiologists. This conference also allowed the audiologists to mind map challenges that face the paediatric audiologist, voice their opinions on the tool, and role play using the tool. This allowed gathering of an understanding of how this paediatric tool is perceived internationally, and observation of ideas that they offered to use the tool clinically.

2.2 Part 2. Audiologist questionnaire

This involved conducting in-depth 1-1½ hour structured interviews with 10 paediatric audiologists, as shown in Table 2. Before completing the questionnaire, the audiologists were to read a summary (Appendix A), to view the tool's components and the supplementary resources, and to view nine videos which included an introduction video, two videos on the development of the tool, an ethnographic video, and five videos of the tool in use by an audiologists and a child. The questionnaire comprised of questions on their reactions to the tool and the videos, their opinions on paediatric rehabilitation and counselling skills, and their opinions on various aspects of the 'My World' tool (Appendix B).

2.3 Part 3. Audiologist interviews

This involved conducting in-depth 1- 1¹/₂ hour structured interviews with seven audiologists (Table 2) and asking a series of questions that covered their first reactions to the 'My World' tool,

their current methods of obtaining information from the child's perspective of their hearing loss, their opinions on the videos and paediatric rehabilitation and counselling skills, and their perceptions on the 'My World' tool. The interviewees were supplied with a summary (Appendix C), the nine videos and a copy of the tool at least one week prior to the interview (see Appendix D for the in-depth questions).

2.4 Part 4. Teacher of the Deaf interviews

This involved conducting in-depth 1- 1½ hour structured interviews with three Teachers of the Deaf (as shown in Table 2) and asking a series of questions that covered their first reactions to the 'My World' tool, their current methods of obtaining information from the child's perspective of their hearing loss, their opinions on the videos and paediatric rehabilitation and counselling skills, and their perceptions on the 'My World' tool. The interviewees were supplied with a summary (as shown in Appendix C) and the nine videos at least one week prior to the interview (see Appendix E for the indepth questions).

2.5 Part 5. Psychologist interviews

This involved conducting in-depth 1- 1½ hour structured interviews with three psychologists (as shown in Table 2) and asking a series of questions that covered their first reactions to the 'My World' tool, their current methods of obtaining information from the child's perspective of their hearing loss, their opinions on the videos and paediatric rehabilitation and counselling skills, and their perceptions on the 'My World' tool. The interviewees were supplied with a summary (Appendix C), the nine videos at least one week prior to the interview (see Appendix F for the in-depth questions).

2.6 Part 6. Hearing-impaired child and teenager interviews

Two young children (Table 2 and 3) were interviewed. Their parents were supplied with a summary prior to interviewing their child, which detailed the background to the tool and the interview protocol (Appendix G). They were offered the option of watching the introduction video, and three videos on the tool being used. The 45 minute interview was composed of, firstly, building a rapport with the child, and then asking them open-ended questions in a semi-structured manner on whether they had difficulties hearing at home, school, and in social situations, and whether they knew and/or used self-advocacy skills in their difficult listening environments. The interview also discussed what their Teacher of the Deaf and their audiologist helped them with and whether they received strategies they could use in their difficult listening environments. Their opinions of the 'My World' tool were also discussed (Appendix H). Parents were also invited to give their own feedback on their thoughts about the 'My World' tool.

Two teenagers (Tables 2, 3 and 4) volunteered to participate in a 1½ hour structured interview. They were firstly supplied with a summary (Appendix I) one week prior to the interview. The interview consisted of showing the teenager the 'My World' tool and five of the videos (the introduction video, an ethnographic video and three videos on the tool being used in the three different environments), and obtaining their thoughts and opinions on these. Questions addressing their experiences with their hearing loss and audiology services were also asked, including a mini-questionnaire on how their own experiences with school, social and home life as a child in primary school (Appendix J). As a thank you for participating, the teenagers received a movie voucher.

2.7 Part 7. Hearing-impaired 20-26 year old questionnaire

One hearing-impaired young adult was recruited to fill in a questionnaire (Tables 2 and 4). This firstly included the participant reading a summary (Appendix K), and viewing five of the videos (the introduction video, an ethnographic video and three videos on the tool being used in the three different environments), and then completing the questionnaire, which addressed aspects of their reaction to the tool, their thoughts of the videos, their own experience with paediatric rehabilitation,

their experiences with school, social and home life as a child, and their thoughts on various aspects of the 'My World' tool (Appendix L).

Participant Number	Research Section	Sex	Location	Work Sector
1	Paediatric Audiologist questionnaire	Female	NSW	Government paediatric services
2	Paediatric Audiologist questionnaire	Female	NSW	Government paediatric services
3	Paediatric Audiologist questionnaire	Female	NSW	Government paediatric services
4	Paediatric Audiologist questionnaire	Female	NSW	Government paediatric services
5	Paediatric Audiologist questionnaire	Female	NSW	Government paediatric services
6	Paediatric Audiologist questionnaire	Female	NSW	Government paediatric services
7	Paediatric Audiologist questionnaire	Female	NSW	Government paediatric services
8	Paediatric Audiologist questionnaire	Female	VIC	Government paediatric services
9	Paediatric Audiologist questionnaire	Female	VIC	Government paediatric services
10	Paediatric Audiologist questionnaire	Female	VIC	Government paediatric services
11	Audiologist interview	Female	WA	Not-for-profit educational institution
12	Audiologist interview	Female	WA	Government educational institution
13	Audiologist interview	Female	WA	Government paediatric services
14	Audiologist interview	Female	WA	Government paediatric services
15	Audiologist interview	Male	WA	Government educational institution
16	Audiologist interview	Female	WA	Previously worked in government child development centre services
17	Audiologist interview	Female	WA	Government paediatric services
18	Teacher of the Deaf interview	Female	WA	Not-for-profit educational institution
19	Teacher of the Deaf interview	Female	WA	Government educational institution
20	Teacher of the Deaf interview	Female	WA	Not-for-profit educational institution
21	Paediatric Psychologist interview	Male	WA	Former paediatric psychologist
22	Paediatric Psychologist interview	Female	WA	Government educational institution
23	Paediatric Psychologist interview	Female	WA	Not-for-profit educational institution
24	Hearing-impaired child interview, 8 year old	Female	WA	
25	Hearing-impaired child interview, 8 year old	Female	WA	
26	Hearing-impaired teenager interview, 14 year old	Female	WA	
27	Hearing-impaired teenager interview, 16 year old [*]	Female	WA	
28	Hearing-impaired 20-26 year old adult questionnaire, 26 year old [*]	Male	WA	

*See audiological history and audiogram in Table 3 and 4.

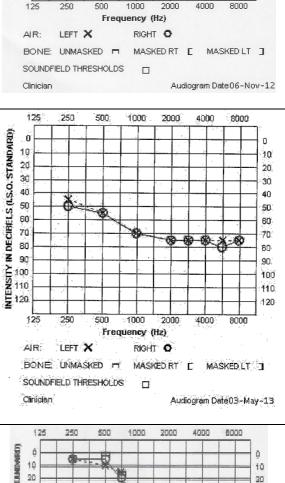
Table 2. Summary profile of participants for each research section.

Participant

Participant 24 (DOB: 20/5/05): An eight year old girl whose hearing loss was diagnosed at birth, and the cause was found to be due to a genetic mutation in connexion 26 and 30. She was aided with hearing aids at 4 months, and then a cochlear implant (Cochlear Nucleus CP810 processor) in her right ear at 11 months of age. She has a hearing aid for the left ear (Phonak Naida III UP behind-the-ear hearing aid) but rarely uses it, and is due to have her second implant in November 2013. Her audiogram shows a severe to profound sensorineural hearing loss in the left ear (see opposite), and she has a profound hearing loss in the right ear.

_S (I.S.O. 50 60 DECIBEL 70 80 ĸ 90 100 110 110 120 125 250 AIR: Clinician Participant 25 (DOB: 18/8/05): An eight year old 125 girl whose hearing loss was diagnosed at birth, and 0 was aided at 12 weeks old. The cause of deafness is 10 20 unknown but is suspected to be genetic due to cousins also having a similar hearing loss. She is currently fitted with Siemens Explorer 500 P behind-the-ear hearing aids and has a moderate to severe 70 sensorineural hearing loss bilaterally.

Participant 26 (DOB: 1/6/99): A 14 year old girl whose hearing loss was diagnosed at 3.5 years and was first aided at 4 years. The cause of the hearing loss is unknown. She has a normal sloping to severe sensorineural hearing loss in the right ear, and a normal sloping to profound sensorineural hearing loss in the left ear (asymmetry in the high frequencies is of unknown cause), and is currently aided with Siemens Pure 300 receiver-in-the-canal hearing aids with a custom tip bilaterally.



Audiogram

1000

125

10

20

30

40

STANDARD) 0 250

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0

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50

60

70

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90

100

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120

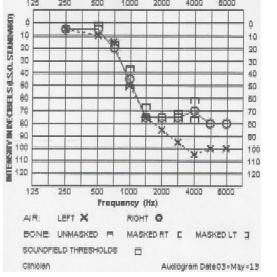


Table 3. Summary profile of hearing-impaired participants A; Participant 24, 25 and 26.



Participant 27 (DOB: 16/11/96): A 16 year old girl who has a mild steeply sloping to profound sensorineural hearing loss in the right ear and a profound hearing loss in the left ear. The cause of hearing loss is unknown. She was diagnosed and aided with hearing aids bilaterally at 4 years old. She underwent cochlear implantation in the left ear at 12 years old, and currently has a Med-El Opus 2 processor on her left ear, and wears a Phonak Naida III UP behind-the-ear hearing aid in her right ear.

Audiogram

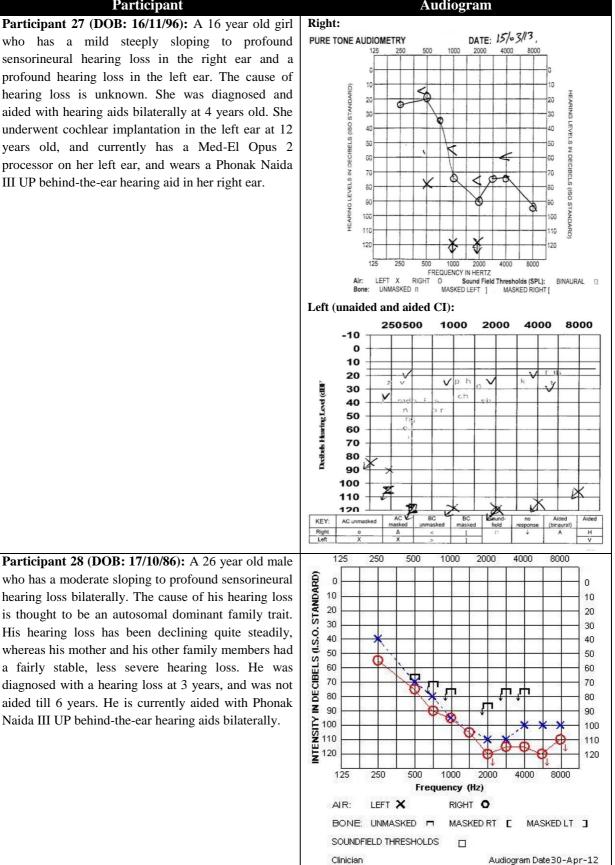


Table 4. Summary profile of hearing-impaired participants B; Participant 27 and 28.

3.1 Oticon Paediatric 2012 Annual Conference (Patient-centred communication) Somerset, New Jersey (19-21st October 2012)

This conference focused on patient-centred communication, and involved the presentation of the 'My World' tool by Karen Parfitt and Melanie Gregory (Ida Institute Audiologists) to American paediatric audiologists. On the first day, attendees were first exposed to a collaborative learning session, where participants developed a mind map of the challenges that face the paediatric audiologist, the patient, and the parents when managing hearing loss in daily life. A discussion of the challenges facing the audiologist clinically was discussed in groups. The audiologists were then introduced to the tool and its development, and how the tool is used in clinical settings and how it could be implemented in daily practice was discussed. On the second day of the conference, participants became familiar with the tool's instructions, components and record form. The ways they may use the tool in different sessions and the challenges they may experience using the tool was discussed. A workshop was then conducted, which allowed participants to role-play using the tool in the clinic.

Overall, at this conference the Ida 'My World' tool was received well, with many audiologists saying that they would find such a tool useful in their clinical practice. When first introduced to the tool, there were many questions raised by the American paediatric audiologists, including: What age/age range of children would you use the tool for? How would you introduce the tool? (i.e. opening statement) What is the time taken to use the tool in a paediatric session? How often would you use this tool? How many times would you use it with a particular child? and, When would you use the tool? (i.e. where does it fit in paediatric rehabilitation programs). This study attempted to address some of those questions. When viewing a video showing the tool in use with a child with a cochlear implant, many of the audiologists voiced their amazement at the interaction between the child and her audiologist, and they liked the concrete use of the tool in suggesting strategies to help the child in difficult listening situations. Some audiologists came up with ideas which included using the tool to direct the child's educators and teaching teachers, however this would be counterproductive in building self-advocacy in a child. Another idea was showing the tool and recordings of its use to other hearing-impaired children, to show that their experiences were similar, and that they are not the 'one and only'. Most of all, the American audiologists liked the fact that the tool showed the child that, with their own resources, they could use this to address their issues. It was discussed that the use of this tool was not so much about time, but on prioritising the child's needs.

3.2 Questionnaire for interstate Paediatric Audiologists

3.2.1 Reactions to the 'My World' tool and current methods of obtaining and evaluating information from the child's perspective

Among the group of ten participants who filled in the audiologist questionnaire, there were varied first reactions to the 'My World' tool, and most of the comments were positive.

"Firstly I thought it might be a little tricky to use and kids might not embrace it or think it was a little bit uncool" (participant 1)

- *"Fun activity to generate an insight into specific listening situations for the child and facilitate discussion"* (participant 2)
- "It would be a fantastic tool to help capture the perspectives of our paediatric clients or even clients that have an intellectual disability but may be able to "tell a story" to express any difficulties that they have in everyday life. I also thought it's an excellent tool but may take a long time to get the information" (participant 3)

"I liked the idea of it as there is definitely a need for it in our clinical practice" (participant 4)

"Colourful and 'child friendly"" (participant 5)

- "I think that any tool that helps us to engage our aided children, and encourages them to actively consider the impact of their hearing loss, and then allows us to further personalize and develop our goals of our program planning would be very beneficial to my clinical work" (participant 6)
- "I felt it was a great way to encourage the child to open up about their hearing experiences as they are often reticent in appointments and the focus returns to adult conversation when they can't provide details of their hearing experience" (participant 7)
- "I was very impressed with the tool and could see lots of potential for use within the appointment. I like how many different ways the tool can be used. I also like that it starts conversations that perhaps may otherwise not occur" (participant 8)

"I thought it was very interesting and potentially a very useful tool" (participant 9)

"That it has good potential as a clinical tool" (participant 10)

These reactions indicated that many audiologists were embracing of the tool, and realised the tool was closely targeted at the child's level.

When asked of their opinions on the following two varied reactions to the tool – "...*it's the best innovation I've seen for years in paediatric rehabilitation*..." to "...*without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain*..." – there was quite a lot of agreement with the both comments.

- "I think it's very negative but not surprising many auds worry about time -I think once they see the tool in action via the videos they will see that quite quickly you can gain useful information from it. It might even save time guessing what is difficult for a child and trialling something that doesn't help" (participant 1)
- "I did wonder how it could be integrated into the usual clinical appointment i.e. in the time frames we currently use. Whilst audibility is obviously important and we need to ensure the hearing is stable and hearing aids are working effectively and moulds fit, I do feel that it a useful tool to gain a better insight into the child's real world and therefore tailor their devices and information to their needs. Often children will be reluctant to express any concerns or hearing issues even when you try and ask numerous questions, so it is easy to just stay with the "clinical" things. This seems more like play but effective" (participant 2)
- "I think the child's perspective is very important in a SUCCESSFUL rehabilitation program. By involving the child and listening to their perspective, I think there's a greater chance of providing a program tailored not only to the parents needs but also to the child's needs. By listening to the child's perspective and responding to their needs directly we could reduce the risk that the child rejects their hearing aids as they are participating in their own rehabilitation instead of being told what to do. Technical audiology is an important part of our job but thresholds and audiological results don't necessarily mean a lot in the real world there does need to be a balance. Without results we cannot appropriately set up and aid but without the clients goals / experience and the ability to problem solve/provide tactics specific to the client an appropriately set up aid may not be as effective as it could be" (participant 3)
- "I think both the comments are true to some extent; whilst we definitely need to have our hearing impaired children 'have a voice' we still need to allow time for 'traditional' audiology as well. It is certainly difficult to have a child or young adult during their appointment voice any hearing concerns they might have and this tool gives them a means to do so; however, the audiologist will need to make time to complete this properly and not skip over areas that may be important to the child" (participant 4)
- "I agree with them both. I guess in more straightforward cases with stable audiograms and circumstances a quick check of hearing and hearing aids could be done allowing time for this important info to be divulged" (participant 7)
- "I agree with both of the comments. It certainly would take up a big chunk of our limited appointment time. However, I believe it would provide some vital opportunities for our paediatric clients to have their say and become individuals. It is critical for a paediatric audiologist to understand the child's perspective and be able to provide the individual support and encouragement needed. As such, in practice, it would be necessary to choose (clinically) appropriate times to complete this tool, ensuring that other concerns and priorities are also met" (participant 8)

There was also a comment in agreement with the first reaction.

"I don't think this tool challenges the traditional components of our role, but rather assists us to ensure that our rehabilitation program is child and family focused. A child's program does not consist of monitoring

audiometry alone, but rather should also take into account the child's individual needs and goals, and be re-evaluated consistently" (participant 6)

There was also one in agreement with the second reaction.

"We already have so much to cover in a paediatric appointment particularly those that are seen annually I feel that whilst it is very important it may take too much time away from other important clinical activities" (participant 5).

An insightful comment addressing both reactions to the tool was cited by participant 9.

"Yes it's certainly new and change can scare people. I think it is certainly a different way of gathering information and may not be suitable or appropriate for use with 100% of clients but it would be a great tool to have in the box and I can see it working beautifully in the right situation" (participant 9).

So among these comments it was suggested that time was the biggest barrier foreseen by paediatric audiologists working in the government paediatric services, but that there was a need for the child to have a voice.

In response to current methods of obtaining information from the child's perspective of their hearing loss and evaluating how well a hearing-impaired child is managing to go about his or her daily life with hearing loss at home, at school and in social situations, the responses were very similar due to all participants working in the government paediatric services. In a paediatric session obtaining this information was usually by informal means.

- "Talking to the parents and sometimes talking to the child (not as much as I should but it is hard to get them to answer" (participant 1)
- "I also use any reports or conversations with the visiting teachers" (participant 2)
- "I ask both the parents and child how they are hearing at school (and socially at school- I always make sure that I include how the child hears their friends and highlight the important of social pragmatics to the parents) and will also enquire as to how they hear and participate at home with TV, conversations in the car at the shops, sporting activities" (participant 3)
- "Currently I tend to discuss social and academic progress at school and at home with the parents (depending on the child's age) and I will then ask the child about their individual classroom situation, and listening patterns and behaviour at home. I also ask them if there is anything specific they would like to discuss today, or any problems they have noted since their last review" (participant 6)

In regards to evaluation, it seemed to also be mainly informal conversations and sometimes the use of questionnaires, and there seemed to be little direct information from the child themselves, or formal means with the child.

- "I will use non formal means such as general conversation during an appointment, I will ring and complete follow up appointments over the phone or email, as well as contacting hearing support teachers to check a student's progress. I will also use formal questionnaires such as the SIFTER [Screening Instrument for Targeting Educational Risk], TEACH [Teachers' Evaluation of Aural/Oral Performance of Children] and PEACH [Parents' Evaluation of Aural/Oral Performance of Children]" (participant 4)
- "I usually ask questions starting open ended and then closed for specific situations I want to check on. I commonly use questionnaires for school especially for FM use or for situations when aids aren't been worn, mild or unilateral losses" (participant 7).

3.2.2 Reactions to the 'My World' tool videos

In most of the questions addressing their reactions to the videos, there was a majority vote, as shown in Figure 7. Most (70%) agreed that the instructional video was useful, but the majority (70%) would like more information on how and when to use the tool and its particular uses. 40% agreed and 40% strongly agreed that the 'Kathleen and her family' video was relevant, and highlighted a need for the tool. The majority also thought that the videos of the tool in use showed a good example of the tool being used. 60% agreed and 40% strongly agreed that good knowledge of counselling skills were necessary to be able to use the tool. An overwhelming 90% agreed that the use of the tool allowed the audiologists to gain meaningful information about the child's perspective of their hearing loss. Overall it was highlighted that a better instructional video is needed to help audiologists to use this tool effectively clinically.

Additional comments on the videos included:

- "It would be nice for the instructional video to be a bit more practically based (i.e. when and where to use and even how to engage child if they are not keen initially)" (participant 1)
- "I found the Kathleen video to be quite touching and true to life; I have a few young adults and 16-20 year olds who report similar situations. I also found it quite confronting that the parents in this video said that they never really understood nor accepted fully what the diagnosis of hearing loss meant" (participant 4)
- "I found the Kathleen video quite informative and it has encouraged me to remember the importance of giving our children constant openings and opportunities to raise any concerns or questions they have. The part about her parents not accepting the loss also rang true for me, as we have several families here who I feel are still yet to fully accept their child's hearing loss, and accordingly we spend just as much time dealing with their cosmetic concerns and denial of the child's hearing impairment as we do in clinical management" (participant 6).

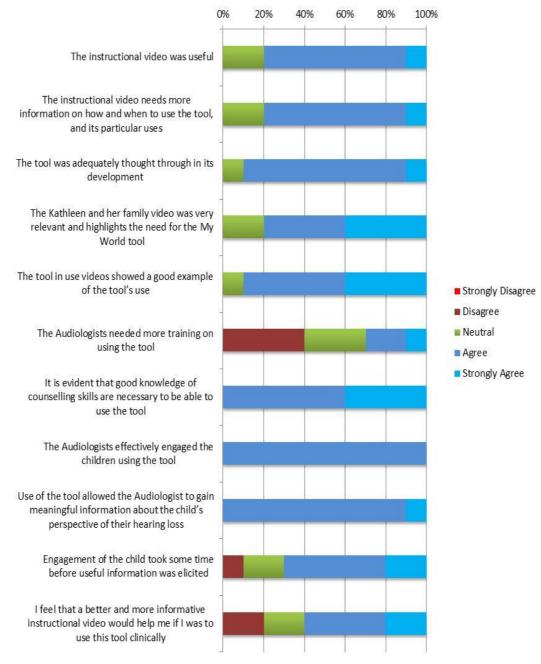


Figure 7. Interstate audiologists' reaction to the 'My World' tool videos; n=10.

3.2.3 Paediatric rehabilitation and counselling skills

The majority of audiologists (60%) agreed that there was a gap in their knowledge about hearing loss from the child's perspective, and 80% disagreed that current methods for counselling hearing-impaired were adequate, with a great number (70% agreed and 20% strongly agreed) feeling that there

needed to be an alternative method for counselling, as shown in Figure 8. Variability was reported in regards to their knowledge of the psychosocial features of hearing-impaired children, as well as being able to counsel the various stages of this development in hearing-impaired children. The majority felt that this tool is within the boundary of their expertise and felt that it would enable them to help a hearing-impaired child to externalise their hearing loss and to obtain the child's narrative.

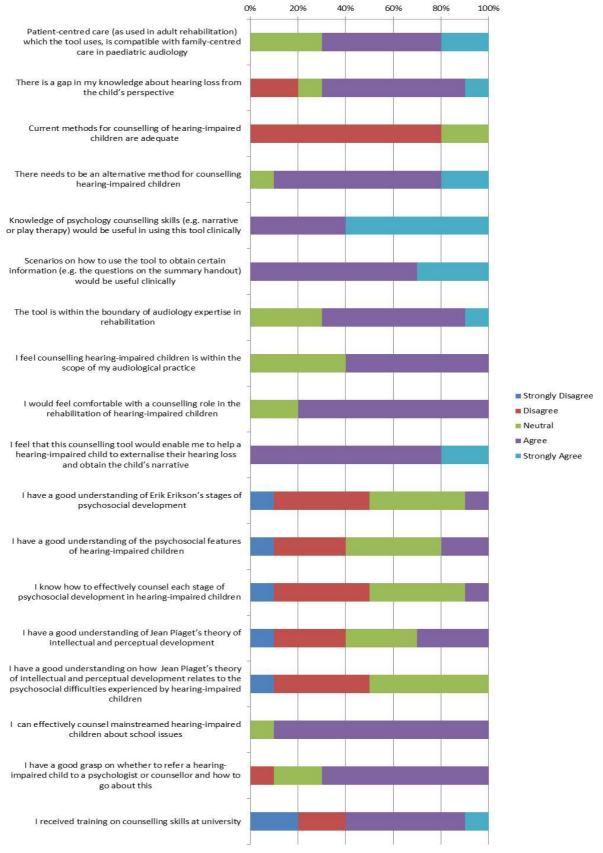


Figure 8. Interstate audiologists' opinions on paediatric rehabilitation and counselling skills; n=10.

3.2.4 Reactions to aspects of the 'My World' tool

In response to the most appropriate age group for the tool, 40% thought the tool should be used for 6-12 year olds, 30% thought it should be used for 3-12 year olds and 10% thought it should be used for 10-12 year olds. Two participants selected other, whereby participant 3 thought that the age should depend on how articulate the child is, and participant 5 thought the tool should be used for 5-12 year olds.

50% of participants selected said that they thought the 'My World' tool should be used by audiologists for counselling on hearing strategies and/or social-emotional counselling, and 50% thought that the tool should be used for these, as well as having a purpose for screening and referral (e.g. to a psychologist).

In response to when and what circumstances the 'My World' tool should be used by an audiologist, 100% of participants thought that the tool should be used at annual reviews, 40% thought it should be used at hearing aid reviews, 20% thought it should be used for cochlear implantation and other candidacy assessments, and 20% thought it should be used for periodic educational assessments. Participant 3 added further comments on when it should be used.

"This tool could be used at any stage of the rehabilitation program where you are trying to gain the child's perspective. You could use it to obtain child COSI (client orientated scale of improvement) goals and then re-introduce it to measure if those goals are better/worse/the same etc." (participant 3).

100% of participants thought that audiologists, psychologists and Teachers of the Deaf should all be using this tool.

In response to whether the participant would use the 'My World' tool as it is currently presented, 40% responded yes, 40% responded unsure, and 20% responded no. In cases where participants responded no or unsure, 60% said this was due to appointment time constraints, and 10% due to reasoning that current clinical methods in obtaining this information is effective. Participants also commented on why they would possibly not use the tool as it is currently presented.

- "I feel without a multidisciplinary approach that we would not be able to effectively counsel the child about the information that we obtain from them; whilst we can obtain good information and set goals we are unable to implement them all into the child's listening environments without a good teacher/audiologist relationship. I feel that we would need adequate training and time available to implement this and without this time we would not be able to use this tool effectively" (participant 4)
- "I am certainly open to using a tool such as this, however I feel that successfully using this tool across a broad range of aided children would require considerable practice (and I could see the first few instances blowing out time wise as I felt out my own rhythm re how to present this for each age grouping, and engage effectively to obtain the desired results)" (participant 6)

"Lack of confidence in asking the right questions at the right time" (participant 7)

"The main problem I think most audiologists will find is that there is not enough time within a particular appointment to perform a discussion such as this. It appears as though it focuses very effectively on one specific situation, but doesn't necessarily open up any other problems that are being encountered" (participant 8)

Many participants saw other potential uses for this tool in rehabilitation, including:

- "It may be good for directing parents who feel their child is doing ok to when they are actually not coping. It might also be good for over-anxious parents worrying about their child's ability to cope – it may show them their child is ok and know how to cope" (participant 1)
- "It could be useful to identify a need for FM systems or other assistive listening devices" (participant 2)
- "Developing and monitoring COSI (client orientated scale of improvement) goals" (participant 3)
- "I think this could be used by school counsellors, teachers and intervention teachers to understand the needs and difficulties of their hearing-impaired students and to help them set goals related to classroom set up" (participant 4)
- "I think classroom teachers could use it to engage more and understand the needs of their hearing impaired students in terms of classroom set up, managing group activities, etc." (participant 6)

- "You could use it before a fitting and post fitting (say of an FM device) as a means of assessing benefit achieved and effectiveness of strategies implemented. That way the child can lead which areas are still behind and those which are improving" (participant 8)
- "To help parents (and the child) understand the difficulties their child is experiencing and how they cope with those situations, and the options they have to manage those situations. This may open the way for more discussion and awareness at home" (participant 9).

Many participants also thought that parents could have a role in the use of the 'My World' tool, such as observation of a professional using the tool. However, there were differing opinions as to whether parents should have a role in using the tool themselves.

- "Parents may be able to initiate more information from their child which could be useful in conjunction with professionals" (participant 2)
- "For me I think one of the reasons I think this tool could be an important part of paediatric audiology is that it is the child telling their experience. Sometimes parents can phrase questions in a way that a child is more comfortable with, and can help support the child's story by supplying information that the child has not thought of - e.g. prompting what happens next in a school day – but there is also the danger that it may skew the response to be what the parent sees. So if this is managed well by the clinician then yes they do have a role – also could help with role plays maybe e.g. "if you're at home and you can't hear what your mum says at the dinner table, what could you tell her?" (participant 3)
- "I think we need to focus on the child, not the adult. If the parent is able to participate in the role playing more often than not, they will take over and the child's voice is not heard. Too often the parent tells us that the child is doing OK academically, when in fact they are not coping socially and this is of greater importance to the child. Parents' goals for the child and the child's goals are two very different things" (participant 4)
- "Yes [parents should use it]. This could allow the parent to identify areas of difficulty the child may be dealing with in the classroom. This would also allow open communication about thoughts and feelings associated with hearing loss and social issues/bullying" (participant 5)
- "Yes [they should] because it would give them an insight into the child's world, helping them to understand and also building a relationship of support" (participant 7)
- "Yes I think it could be very useful but I would be concerned about its use/potential misuse or overuse by some parents" (participant 9)
- "Not without training" (participant 10)

100% of participants felt they would feel comfortable counselling hearing-impaired children using a tool in their rehabilitation in regards to hearing strategies, and some participants felt they "wouldn't mind a refresher on Piaget and Erikson theory in relation to hearing-impaired children" (participant 1) and one participant responded "[using a tool for] emotional counselling, no" (participant 3). Others said "I feel uncomfortable counselling a child with no real training in paediatric counselling (with regards to the emotional wellbeing of the child.)" (participant 4) and "With further training which is specifically directed towards paediatric counselling (for both the child and their family) yes I feel I would enjoy implementing increased counselling as part of my overall program" (participant 6).

In response to being asked whether the 'My World' tool would be successful for bridging the gap between the roles of audiologists and psychologists, many participants believed that it would.

- "Yes I do, it may be a more non-threatening way for audiologists to counsel where they may be scared to use "traditional" methods as they are not qualified counsellors" (participant 1)
- "It would help give a construct to a discussion about how a child is going in terms of hearing management and also how a child is going emotionally. So perhaps it could close the gap but still audiologist does not equal psychologist" (participant 3)
- "Yes, as it could be a useful tool for basic counselling" (participant 7)
- "Yes I can see that there would be an application for it" (participant 9)

"Yes so long as the audiologist has enough counselling skill" (participant 10)

Other participants were more sceptical on the tool playing this role of bridging the gap.

"It may make cross referral easier, however I do not feel this tool alone brings our counselling ability closer to that of a psychologist, as we are not trained psychologists, and we often must rely on second hand reported information from both children and their parents regarding academic and social progress" (participant 6) "Given we are not trained psychologists I feel there is a need for counselling from a trained counsellor when developing a rehabilitation program with a hearing impaired child" (participant 4).

Participants were asked to identify what they thought would help this tool be framed so it is more intuitive for an audiologist to use, and what skill or resources they felt could enhance the use of this tool which hearing-impaired children. Participant responses varied but all felt there were some skills or resources that would help.

"Training on questioning skills" (participant 1)

- "More guidance in how to introduce the session with the child and family. Families often have expectations of what will be covered in their child's appointment especially if they are only seen annually and come with a "shopping list" (participant 2)
- "A greater knowledge of the social-emotional impact of hearing loss from a child's point of view. I also feel there is a need for children to access counsellors with regards to discussing more of the social-emotional issues that may arise and I think we need to look more about what happens specifically in Australian clinics ... not all the pictures were representative of what happens in Australia (like the yellow bus and badminton set)" (participant 4)
- "iPad app or a briefer version that can be broken down a little more" (participant 5)
- "Have materials that are individualised for separate age brackets, have tools (i.e. picture of toys etc.) that are more relevant, and should also include technology usage discussions i.e. iPad/iPhone or similar. It could also be automated or presented as an app as this would engage more with older aided children" (participant 6)
- "Different figurine style so they are easier to manipulate... Would be great in a digital media format like roleplay computer games, etc. and child selects their 'players' and they go into the different environments. Then they would be able to click on things e.g. TV and hear sounds, etc. Could use on a tablet or laptop for portability. I feel this format may be more appealing to children who are of this digital era" (participant 7)
- "More training on how to counsel children once a problem area/situation has been discovered. I think the main thing I've gained from watching the videos is that the problem is often not we would be expecting. It's one thing to be able to ask the questions, but having the confidence and resources to supportively answer and handle the questions is a completely different matter" (participant 8)

Participants offered more example questions to those given in the summary which could potentially be addressed by using the tool.

"How does the child use strategies by themselves?" (participant 1)

"Is the child coping well in their natural environment?" (participant 1)

"Does the child need assistive listening devices in certain areas of life?" (participant 3)

Participants also filled in a table, rating various aspects of the tool, as shown in Figure 9. In response to most of these questions, there was a majority vote. The majority felt that more information is needed on when (40% agreed) and how (80% agreed) to introduce the tool. 40% agreed and 20% strongly agreed that the packaging of the tool should be different for different age groups. The majority (50% agreed and 20% strongly agreed) also felt that there is a multi-disciplinary approach needed with the use of this tool. All either agreed or strongly agreed that there was a use for the 'My World' tool clinically and that it could enhance/improve the outcomes of paediatric rehabilitation. 40% agreed and 40% strongly agreed that the tool could be used to obtaining both the child's perspective of their hearing loss and actually helping the child. There was a majority vote that more paediatric skill resources were needed clinically. 60% agreed and 30% strongly agreed that play and narrative therapy techniques would be useful if they were to use this tool clinically. Therefore, there were many things that the audiologists felt which need to be improved with the 'My World' tool, knowledge or skill-based and its development.

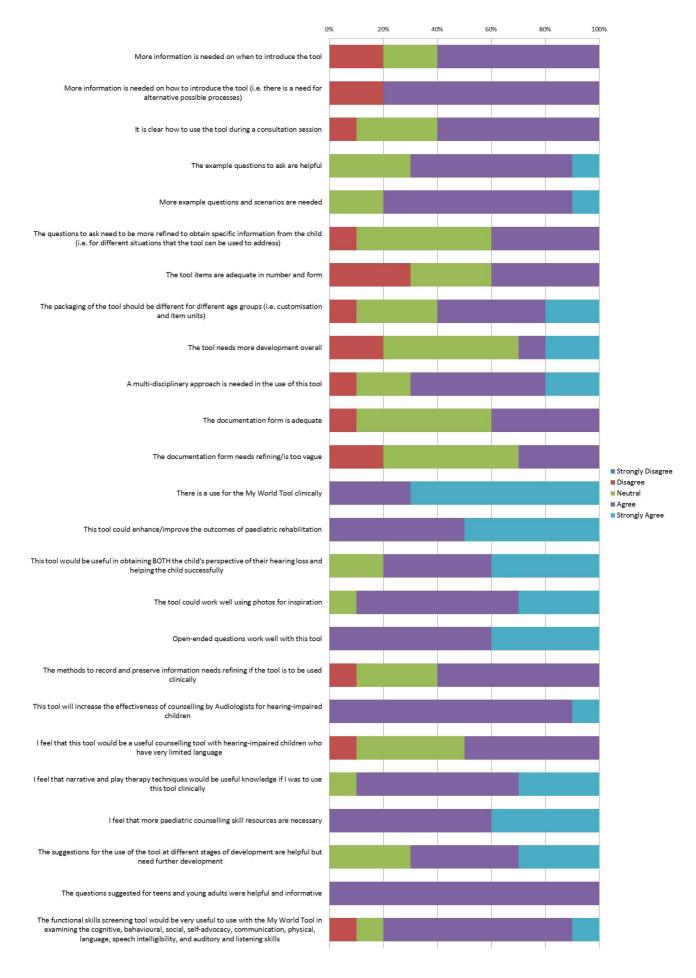


Figure 9. Interstate audiologists' opinions on aspects of the 'My World' tool; n-10.

3.3 Audiologists interviews

3.3.1 Reactions to the 'My World' tool and current methods of obtaining and evaluating information from the child's perspective

The first reactions to the 'My World' tool by the audiologists were positive, but some of the audiologists could initially see some problem with the tool.

- "I think it could be good in certain situations but quite specific, I don't think it's obviously practical for everything for everyday and everyone. I think it's a good initiative, I think some people will love it and want to use it and other people will just not think it's relevant to them – it depends what the clinician does in their day to day stuff" (Participant 11)
- "The first time I saw it I thought it was quite interesting, fiddly though. I have to say all little parts in the tool are fiddly. For an audiologist, particularly a clinical audiologist I don't think it's very useful. That would have been one of my first impressions. The overall idea I quite like, I see uses for [the tool] but not necessarily for an audiologist unless they work in an educational audiology setting. For a clinical person I think it would be much too time consuming" (participant 12)
- "I thought it was excellent. I really liked the idea of using the tool as an interactive medium with the kids. But conversely I was worried about how I was going to find the time to use it in my appointments because I'm already struggling to keep to time" (participant 13)
- "It looked like something very interesting and novel and we could see the value of using it in our clinic. But for some reason just with all the routine work that comes through no one actually took the box out and used it in the appointments" (participant 14)
- "From my experience in education I thought it was quite relevant. It's a very useful tool because it allows the child a very developmentally appropriate way to express themselves when we ask them questions about their communication in their learning space. It is concrete which is perfect for children, and to tell us their own story through play forms, and so it's quite a nice tool. It's such a novel approach and very child centred" (participant 15)
- "What a wonderful and dynamic tool" (participant 16)
- "I thought it would take a long time to use in a clinical environment, and I also wondered what parents' perception would be of it" (participant 17).

In responses to comments by audiologists to the tool from '...*it*'s the best innovation I've seen for years in paediatric rehabilitation...' to '...without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain...', the audiologists responded:

- "I think that's true but if you only have one or two appointments with the kid The first one doing the audiometry, finding out the hearing loss and explaining the results to the parent, and the second one's the fitting where you would fit in this, so if you have the luxury of more time to do rehab. I don't think it's a tool to use for start, I think it's when they've been wearing the hearing aids for a while and get feedback then. So for people who see kids regularly and they have time to do that it'd be great but I can see why many people wouldn't find the time" (participant 11)
- "That's to me very typical of a clinical audiologist and I would agree with them. Hence why I work in educational audiology because I don't think you're sacrificing anything. I think functional assessments are much more appropriate. You need to be thinking about the whole child, you need to be thinking about how they're relating to people; it's not about the ears in hearing loss. It gives you an idea and that's it" (participant 12)
- "I guess that's my comments also. I think that the tool is great because I can see an interaction and rapport with the child is very important. And for some children it's just as important as having a good rapport and an awareness of their hearing loss and how it's affecting them. It's just as important for some children as having good audibility. So I think if we could find a way to do both in an appointment that would be wonderful. But obviously our primary aim is to ensure access to speech sounds and I guess our appointments are heavily focused to that and we don't always necessarily take the time to know the child as well as we'd like to because of the time restraints" (participant 13)

- "You always want to find that balance between ticking the audiology tickboxes as well as the holistic approach of the child, and by holistic approach I mean how do they feel about everything, how are they actually coping with their hearing aids on a social side as well as an emotional side" (participant 14)
- "Audiometric information only tells you so much. I mean these children have been tested, tested and re-tested dozens of times and nothing's really changed. For my perspective I need to know how they operate in their learning space, and so the hearing test tells me nothing at all for this and this is why all our reports include lots of functional assessments. So rather than sacrificing audiometric information it would actually complement your whole battery of tests" (participant 15)
- "The role of an audiologist can be many things. [This tool is] not a challenge to an educational audiologist or even one who is managing the aids and trying to maximise understanding in noise" (participant 16)
- "I could see the importance of it being used within a program for a child, so I think that we need to make time to use it, that you can gain a lot of valuable information from it, so it's important to factor that in and actually make time in the child's program" (participant 17).

The current method of obtaining information from the child's perspective of their hearing loss in a paediatric session and evaluation on how well a hearing impaired child is managing to go about his or her daily life with hearing loss, at home, at school and in social situations was reported by the audiologists (similarly to those who completed the questionnaire) to usually be done via informal discussion and questionnaires.

- "The therapists might but as audiologists I don't know if we really ask the kids all that much. In terms of evaluation we use questionnaires – PEACH or SIFTER and LIFE. We also try finding out how they're going through speech tests to get a measureable idea of what they're hearing or not. In terms of getting a general idea of how they're going of social situations – this is not really covered" (Participant 11)
- "I often just informally ask the child, "How are you going with your hearing aids", "What do you like about them" and "What don't you like about them". I find those really simple questions are a good way for the child to open up about them. There is one form that we use that is for FM systems. It's for young children to get an idea of whether the FM is worthwhile or not. 'Student Opinion of FM benefit'" (participant 13)
- "Typically we go straight to the parents to get their opinions, and sometimes we will just ask the children general questions, such as how are they going with their hearing aids" (participant 14)
- "You've caught me there, because it's usually through assessments, and there's no real one-to-one sitting down discussion like I saw with the tool. I thought that the tool was quite inviting for the child. It's mostly from the perspective of checklists (such as the SIFTER or the LIFE) and these checklists are completed by the school teachers or the parents, so in fact we don't really get the true perspective of the child. However, it's something that you usually cram in at the end of an appointment and it's limited with closed sets of questions. With the 'My World' tool I think they can show their world with not so much limitation as these questionnaires" (participant 15)
- "We'll ask a child, for older children we will ask them so I would say from Primary school upwards we would ask them, and you get a mixed varied response from the child depending on how outgoing they are. For the younger ones we rely on parent feedback and teacher feedback if we have access to that. There's nothing sort of really structured, we use the COSI tool to provide a goal-based program. Sometimes you don't always get very open responses from them with just a discussion, and they often say yeah everything is going okay" (participant 17).

3.3.2 Reactions to the 'My World' tool videos

There were varying responses to the 'My World' tool instructional video, as well as thoughts on ways that it could be improved.

- "Good demonstration of how it would work in an ideal situation if you're seeing the perfect child. It didn't tell you exactly what you needed to do as a clinician to get it going. I'd prefer an instructional video talking through what you as a clinician would do and how you would get the child to start chatting and using the tool. It all depends on the kid - If you have a great kid who is extroverted and chats away or if you get an introverted kid who just sits there and looks at the board – there needs to be more explanation on how to commence and how to engage" (participant 11)
- "I'm not keen on instructional videos myself if that's the only method. I think that people who are going to use tool need to be with somebody who is very comfortable with it who can demonstrate to them how and why. I think you need to demonstrate to people how it's used and also mentor people in how to use it because

there's a lot of stuff that can go on with that and you need to be very clear on how it's going to be managed and why you're going to manage it this way" (participant 12)

- "I think anyone can Figure out from looking at the box how you're going to actually use it. What I wanted modelled was different examples on when and how it could be used because there are obviously so many different applications for that. I wanted maybe even just a list of ideas of how you could make it work for different end goals and have these explained in an instructional video" (participant 13)
- "The instruction tool was good on a basic level, but I think that those who want to use this tool to their maximum capacity I think a detailed video instruction would be useful" (participant 14)
- "I thought it was fine, but I thought the tool was intuitive enough without it. It doesn't hurt as an introduction though. Perhaps it could be improved by showing how to use the tool for different situations" (participant 15)
- "Yes it was okay, however more detail and topics needed on how to use the tool" (participant 16)
- "It was a nice summary of everything that I'd read, so all the information in the tool that I read before looking at the video it was a nice summary of that. But I don't think it's adequate, from that I don't think that I could go away and use the tool - I would like to see an example of how that is used or have it explained more" (participant 17).

Many of the audiologists interviewed could see the relevance of the Kathleen and her family video to the 'My World' tool.

- "Yeah that video was an eye-opener, I thought it was really interesting how her family pretty much went about things their own way thinking it was the best way for them but clearly it wasn't the best way for Kathleen. I guess it gives you the motivation to use this tool in early age so you don't end with children like Kathleen" (participant 14)
- "Yeah, I thought it was quite good, especially to show the emotional side, and it was great to have the parents there sharing also. Socially and emotionally the video did highlight a need for the tool" (participant 15)
- "Yes indeed [it was relevant], very scary. This should be shown to ALL audiologists" (participant 16)
- "Yeah I did [think it was relevant], I found that really interesting that video, and it did actually highlight that while the parents thought they were doing what the child wanted, the child on reflected realized what she wanted at the time wasn't necessary what was best for her. So I think it did highlight that you know some of the questions that we raise as opposed to what's best for the child and what as professionals, we think is best for the child. Yeah the idea of the tool to really explore what the child is thinking is a really great idea because it helps to give some insight into having a better understanding of what the child actually needs when they may not be fully aware of themselves of what's best for them" (participant 17)
- Other audiologists felt quite differently about the Kathleen and her family video.
- "I don't think it highlighted a need for the tool. I don't think it was relevant to the 'My World' tool specifically and it kind of told us stuff that we already knew – how parents and families need to talk about hearing loss and stuff and I don't think it linked back to 'My World' tool. Although, it showed a need to listen more to the hearing-impaired person" (participant 11)
- "I think this highlighted a need more in a psychology area. And if you want the tool for that [type of counselling as an audiologist] I think it is totally inappropriate. I don't think it's a need for this tool [that it highlighted]. I think it is a need that you need to be using a team approach when you're dealing with families that have a child or person identified with hearing loss" (participant 12)
- "It certainly highlighted to me that Kathleen's family didn't really understand what she was going through. I don't know necessarily if that says that this tool is the thing that is needed" (participant 13).
- When asked about their opinion of the videos of the tool in use, the audiologists responded:
- "Yeah the videos were good, I actually enjoyed them. All the kids were quite engaged in it. I don't think it gave much audiological information than was already known – it seemed more psychological – i.e. how did that make you feel?how you would use that in your audiological tuning of a hearing aid, I'm not really sure" (participant 11)
- "We have quite a variety of children who present very well. We also have children who have learning problems and hearing loss. So that's another one and their language is quite difficult so it would be difficult to use that tool with them. We have children who are using AUSLAN so that would be quite interesting. What they've demonstrated here is a very oral perspective on things, and that's fine. If you're a listener, if that's the kind of education you've had then that's what you are going to be using. But also you do use speech reading so that kind of commenting wasn't really happening either" (participant 12)

- "I really enjoyed watching them I thought they were excellent. It was really, really good just to see how well the kids took to the tool. They felt that they were really in control, you could really see that. I would love to use the tool in my clinic if I had the time to do it. Who doesn't want to sit down and play a game with a child about their life, I'd love to do that. It was really great that you got to know them but you got to play a game at the same time, but it's an educational game. I found it really, really good as well to do that in front of the parents" (participant 13)
- "You know I thought those videos where the audiologist was using the tool with a child were really valuable. Those kids were quite articulate, and not all of our children are that articulate. So I guess they showed model examples. In the real world I'm sure there'll be times where we try to use the tool but not get the information useful. To balance it out I think there really needs to be examples where the kids aren't so well spoken or as willing to participate" (participant 14)
- "It was great to see the children immersed in their own world, and using concrete objects to explain their scenarios and being in control of the situation. I think it would be good to see examples where the child is not such a good oral communicator and see how the tool is modelled with them. It also would have been insightful to see examples of the tool being used with teenagers" (participant 15)
- "The videos were really good, and they showed different aspects of difficulty, and function from the child's perspective" (participant 16)
- "Yeah some of the videos I felt showed a really good use of the tool and I thought it was quite sort of obvious from the video what the next steps might be for a program for the child" (participant 17).

The audiologists were asked to comment on whether they thought the audiologists needed more training on using the tool, so it was intuitive to use, to which they responded quite variably:

"No they all seemed quite confident and good the audiologists in the videos" (participant 11)

- "My view at this point in my life is you either have it or you don't. You either know how to do it or you don't. And you're either comfortable doing it or you're not. I'm not so sure who is not comfortable not doing is going to get more uncomfortable. They might be uncomfortable with the pieces and all that and knowing exactly what it is. They may have been uncomfortable being videotaped. So I think it would be a fairer thing to videotape lots and lots of sessions and see if they improve over time" (participant 12)
- "Overall I thought they were pretty good, there was one lady I thought she needed a little more training. I think she didn't know how to ask the questions well, possibly" (participant 13)
- "No I think they used the tool quite well. I could tell they have been using it and were quite familiar with using *it*" (participant 14)
- "No, I think they were pretty comfortable, but in some question areas of the examples I was thinking is that really audiology, and perhaps that's more of a psych thing" (participant 15)
- "Yes, some people may use it instinctively, but for others help and guidance is needed" (participant 16)
- "I think that anyone using this tool is only going to get better at it with experience. It think one of the difficulties with all of these sorts of tools is because it is more sort of a counselling tool, it's knowing what the right questions are to ask, and I think that you get better at that with experience. However, I thought they all did a good job of using the tool" (participant 17).

The audiologists also gave varying responses on whether or not they thought that the tool allowed the Audiologists to obtain meaningful information about the child's perspective of their hearing loss:

- "I don't know, probably not I don't think any new information was gained audiological information. I think it's a great tool for the parents more than a clinician" (participant 11)
- "On the people who felt comfortable using it yes. I think it's probably a thinking tool for an audiologist. It is perhaps forcing them to think outside the box, that is the booth. But the interpretation of that information sometimes can be tricky. How comfortable you are with understanding what you are getting is the other half of that. I think this is a sophisticated tool that probably needs a lot of mentoring on how to use and what does that information mean" (participant 12)
- "I think so, it definitely gave them some insight into where they can hear and where they can't and what makes it easier for them to hear and what makes it harder for them to hear. That's all interesting information. From our point of view how is that useful? I guess we would have to take that and use that to counsel and to give an idea of what's realistic and what's practical in the child's life. I don't know if it would affect what we did for the rest of our appointment, I think we would run the appointment the same way, maybe just use that information just to council a bit" (participant 13)

- "Yes and no, sometimes it gives the child opportunities to give too much information that's not really relevant. It's up to the audiologist to hone in and try to be more specific in their questioning" (participant 14)
- "Yeah definitely, as it was from the child's perspective and that's the most important thing that needs to be taken seriously" (participant 15)
- "Yes. The child was able to use a concrete tool where descriptive language may not be as affective" (participant 16)
- *"Yeah I think it did, yeah. I thought it was a really good tool for that"* (participant 17). Other insightful comments on the videos by the audiologists included:
- "I thought it was really well used for practising of modelling behaviours. That is a really a good use to actually encourage children to be their own advocate, which I'm really passionate about. I think that would be a really great use of it because sometimes kids just need a little bit of a helping hand to say "maybe say this when you're in this situation"..." (participant 13)
- "I liked the fact that the parents were also involved and gave feedback, as it's a great learning experience for everybody present. Having some more direction in the videos, such as instruction wouldn't hurt" (participant 15).
- "I would have liked probably a little bit more about the case history of the child, and possibly what prompted the use of the tool. I did really like the part on the end of the video of Chloe with her parents, where they asked parents what they thought of the tool. That was quite encouraging because as I mentioned at the beginning one of the initial thoughts I had was that the parents might think that we're not actually doing anything with the child, and what's the point. I'd love to see a video of it being used with a teenager" (participant 17).

3.3.3 Paediatric rehabilitation and counselling skills

In response to being asked to what extent they felt that counselling hearing-impaired children should be within the scope of audiology practice, all of the audiologists felt that they had some role, particularly in relation to basic counselling around hearing loss and amplification:

- "It should be extremely important, it should be covered extensively, and it should also be re-visited often. I think when you're specifically talking about the hearing loss and the impact that that has on the on the person's life that should be the audiologist, but perhaps when you're crossing the line to how you feel and social depression and isolation then maybe that would then lead on to a psych" (participant 11)
- "I think audiologists should. Audiology came from World War II as a rehab thing. It only became a medical model or very definitely a tool thing as equipment has become more sophisticated, so there's been a big change on what the focus of audiology originally was. So now that the rehab and habilitation has been offloaded onto people. I personally think there should be parts of that coming back. Not for new graduates, I'll be very specific. I'd be very surprised to find a new graduate that could handle that. I think they need to work on their skills with adults and if you are going into paediatrics then you need to be mentored. The same with adults, you need to be mentored and have very experienced people help you and make sure that you are doing what needs to be done in the system you're in" (participant 12)
- "It is part of our job and everybody should do it. I think everybody should do it. I think if you just put hearing aids on somebody and said off you go, that's not doing our job. It's important that we educate about the hearing loss, about what it means for them. Whether you have a mild to severe hearing loss or you have a conductive hearing loss or a sensory neural loss we need to explain the actual audiology point of view, the actual results of what we're getting and then try and relate that to their life" (participant 13)
- "We're not trained as counsellors, so we rely heavily on external agencies who have a child psychologist to provide that sort of specific information. We can provide basic counselling about the hearing loss to the child, explain what the hearing loss means to the child, what they can and can't hear, give them some management strategies. But in terms of the nitty gritty counselling that really has to come from an educational child psychologist" (participant 14)
- "Primarily, to validate their hearing loss and give counselling around hearing loss and hearing aids, but maybe we should be doing more of that [addressing the emotional side], as we are the ones who have the training on knowing the hearing loss side of things, but I think it need to be done in partnership with a psychologist together. I don't think the psychologists should handle it all themselves though, so it should be a mutual team thing – a disciplinary approach. In my opinion personally I don't feel comfortable addressing the emotional side of things in a session" (participant 15)

"An important part, as communication strategies is part of audiological management" (participant 16)

"I think it should be, it is part of, should be part of the hearing rehabilitation program, to actually help that child to adjust and live with the hearing loss. And be comfortable with advocating what they need to help them through school, and through high school education and employment and things like that. I think that audiologists need to become more comfortable with actually asking those "how do you feel" questions. I think it's a cultural thing where we don't accept emotions well, and don't openly display emotions, and therefore we can be uncomfortable about asking other people about their emotions" (participant 17).

In response to the question on when should we be transitioning from family-centred (looking after the interests of the family) to patient-centred care (putting the interests of the child first), or if the two compatible, the audiologists commented:

- "I think they're compatible, I don't think there's a set time; I think it depends on the kid and their different maturity levels. I would try to get the child as independent as soon as possible, so I can start to address the child, instead of asking about the child via the parent while they are sitting there, but then you might have a very immature 12 or 14 year old who maybe can't - so no set time – they are not completely separate from each other anyway" (participant 11)
- "I think it is not a fixed time and that the two are compatible and continual. However, I am not totally convinced that we are fully family-centred as usually not all members of the family are present [at appointments]" (participant 12)
- "They probably are compatible. It's a fine line balancing the needs of the parent and the needs of the child" (participant 13)
- "The two are always compatible, even in adult rehab we include their family and significant others, so it's not mutually exclusive. I think this tool could potentially bring in patient-centred care earlier, but there still needs to be a balance of your focus of attention" (participant 14)
- "This is a really good question. I think we are starting to transition from early childhood into primary school, and primary to high school, as these are big steps for the child, so I think it should happen when there is the need for it. I think the tool could bring patient-centred care in earlier, as that component is often lacking" (participant 15)
- "The child should be encouraged to participate as soon as possible. In adult rehabilitation we should always be encouraging family involvement. Hearing loss affects all in the family at all ages" (participant 16)
- "I think it should be a gradual transition, so I think we should start looking at what the child needs and wants, a lot earlier than we have been. So yes I think, you know, once the child's able to express themselves and communicate more it should be a more gradual transition where more focus is placed on the child as they grow" (participant 17).

All seven audiologists interviewed reported that they would feel comfortable counselling hearing-impaired children using a tool in their rehabilitation, as *"kids react well to tangible things"* (participant 11), and as *"part of working with children is talking to them"* (participant 16).

When asked whether they perceived a gap between the counselling by an audiologist and a psychologist, and if so, did they think such a tool would be successful for bridging the gap between the roles of audiologists and psychologists, some audiologists agreed that indeed there was, and others reported that they were unsure, citing very similar reasoning:

- "Yeah I don't know, I don't know what a psych does at all so I wouldn't know. I think it would helpful to know what extent a psych covers with a hearing-impaired child and therefore if the tool could be used to potentially fill any gap" (participant 11)
- "Yep, there's definitely is a gap. I think it goes back to training, I think you can be alerted to things as an audiologist and realise that something is up. The child may not be saying it to you, or may be saying it to you. I see myself as an information gatherer, and then referring it on to the appropriate people. The minute you start getting into emotional things and higher level things it's just different. It's a higher level that is not my expertise. I can empathize to a certain degree. I'm not hearing-impaired so I can't do a lot of that but I think it's then you move them to people who are capable dealing with it. I think it depends on the person using the tool, how well they perceive what is happening with this tool [as to whether it could fill the gap]" (participant 12)
- "To be honest I don't really know enough about the counselling that psychologists offer, so I'm not really well placed to answer that. I think it would be really helpful to know what extent of counselling psychologists cover" (participant 13)

- "I've never sat in on what a child psychologist does with a child so I don't know what their scope of work is and if there's an overlap or if there's a gap. I guess that's kind of the unknown for us. It's hard to notice much, we don't get much feedback from the other agencies in terms of what they're done with the child in terms of counselling or with the family. It's only really if the family volunteer information to us, so we don't have any idea of what's covered" (participant 14)
- "Yes I do, definitely, because they are two different disciplines. I think the psychologists are excellent at looking at that social-emotional sphere or aspect but they would struggle with the audition and auditory function where we can interpret the test results and make recommendations, that is the technical aspect. The two professions might derive different information from the tool, so perhaps [the tool] might offer some bridging with teamwork" (participant 15)
- "I don't really feel there is a gap the roles are different. Psychologists many not understand about hearing aids and [audiologists] don't do psych assessments" (participant 16)
- "Definitely [there is a gap], as in I don't think audiologists are terribly skilled at the counselling side of things. Umm yes so I think yes there is a gap. I certainly think audiologists could improve the counselling skills. Yeah I do [think the tool could help to bridge the gap], I think it provides a sort of means for, a semi structured way for the audiologist to actually start that counselling and I think it provides them some guidance as in to what to ask, and what to look at with them, which I think is one of the problems with the clinicians, they don't necessarily know the right questions to ask to get the information from the children" (participant 17).

All seven audiologists felt that there was a gap in their understanding of the child's perspective of their hearing loss, for example:

- "Yes, as I've come across many kids who don't understand their hearing loss at all, even teenagers one that can't tell you what there hearing loss is, and two they really don't know what the effects or impacts of that are" (participant 11)
- "Yes, definitely. Particularly if it's a high performing child, someone with very good skills. I think people forget and don't understand how much energy and effort is going into what this child is doing" (participant 12)
- "Yeah there probably is because it's not something we routinely seek to obtain" (participant 14)
- "Yes, as probably not lots of people have thought about it much. Too bad, we need to. We also need to get [the child] talking about it and how to control their own world" (participant 16).

The audiologists were asked if they had knowledge of Erik Erikson's stages of psychosocial development and Jean Piaget's theory of intellectual and perceptual development and how these relate to the psychosocial features of hearing-impaired children. The responses mainly suggested that they didn't know a lot about these or how they relate to the psychosocial features of hearing-impaired children:

"I've heard of Erikson's, but I don't remember anything about it" (participant 11)

"Yes, because I trained as a teacher. But that would be many, many years ago. I think audiologists should all go through that. Now days with children with hearing loss, we are getting children who are surviving. Years ago we a lot of these kids would have died. Now we have children coming through who have so many problems, hearing is one part of that. Having an understanding of normal child development would be quite helpful. I think it gives you better perspective" (participant 12)

"No I haven't heard of them, but I think it would be helpful to know" (participant 13)

"Nope, they might have covered some of these theoretical models in uni but it's not something that we specialize in so we don't' retain that information. Maybe on a basic level they would be good to know" (participant 14)

"Back when I did my education diploma, these were taught but no I can't recall these now" (participant 15)

"Not extensively, but I have a good understanding of general development, especially language development" (participant 16)

"No, not enough. I think that having a refresher of these with using this tool would be great" (participant 17).

The audiologists were asked whether they had any extra training in counselling or psychology. The responses were quite varied, from none at all to workshops/conferences to some training in university:

"No, however I think it would be extremely helpful to have some training and knowledge in these areas" (participant 11)

- "I've certainly had a lot of professional development (PD) days. I wouldn't say specific to hearing loss though. I go to a lot of PD days on learning disabilities and autism and others because that's the need, and within those days there is a lot of counselling aspects with working with families" (participant 12)
- "Certainly at uni we learnt about counselling and also just through my own reading. It was certainly touched on in uni but I don't think it was touched on enough. I think there definitely could be more counselling in audiology courses" (participant 13)
- "Not really, although you might get one or two presentations at the state conference in general but it's not a big highlight unfortunately" (participant 14)
- "No I haven't had any" (participant 15)

"Yes, various small workshops over the years" (participant 16)

"I only did some psychology units through uni, but they were sort of like first first/second year units. Also, we've had some counselling sessions run by Vic Deaf though work, so we got from their perspective what parents need going through the journey, but not specific information on counselling hearing-impaired children" (participant 17).

Audiologists were asked if they felt that there needed to be an alternative method for the counselling of hearing impaired children or if they felt current methods were effective. They were also asked to highlight if there were any issues that were not addressed with current clinical methods and whether the current methods could be combined with the 'My World' tool. In response, most audiologists felt that there needed to be an alternative method, and also felt that the tool could be combined with current methods:

- "Yeah, I think that one size fits all is not right with audiology and what works for one kid and family may not work for another, so that would be great. I think so yeah [that the tool could be combined with current methods]" (participant 11)
- "I think we do probably [need alternative methods], because we [educational audiologists] are the end of a system here. We are an end point in education. They have been to lots of other places and then they come to us. So we have to pick up or take on things that have already been setup elsewhere. So if you're asking me if other people have done a good job I would say to you no, I do not think that they have. I think they [clinical audiologists] focus too much on the ears, they're not looking at the person, the child as a whole and what the family needs. And if they are looking at that then they haven't moved them onto the people that they need to move them onto. And I think that's the difficulty. It's not a fault thing, it's a matter of resources. Here in WA we tend to use a medical model for audiology. In a medical model there is no provision, it's a fix it thinking. Let's put the aids on and we've fixed it. There is no provision to looking at families, for helping them through, it's not what it's about. A medical model is get them in, get them out and time is money. I think if people used it they might identify better, so yeah the tool could be combined [with current methods]" (participant 12)
- "There's always room for improvement. I think in the time we're given, I just don't know how you can counsel more. We're so short of time in appointments, however, just to sit and counsel is really important. In the earlier appointments when someone's first referred to us we have a lot more time and we can spend that time counselling them. But in the subsequent years we don't have as much time available. We aren't necessarily seeing the children as much as we should be seeing them because we just don't have the staff at the moment. It's more of a time factor than needing alternative methods for us" (participant 13)
- "Sometimes it's a case by case basis and what the child needs. Some children will benefit greatly from the 'My World' tool, others won't get the information that you need and you have to use other tools at your disposal, so perhaps! Can it be combined, yes is some cases" (participant 14)
- "I probably don't think there is enough counselling, or that there is a lack of or an inadequate amount of counselling or it's not done properly, so yes I do think there needs to be alternative methods. Good counselling taught in audiology courses would be good and I'd like to see more of it in there particularly on how to empathise with the clients and their parents. Yeah I guess the 'My World' tool could be combined with current methods, as it is a good education tool even for the child themselves" (participant 15)
- "Yes, the 'My World' Tool is a good start for an alternative method. Obviously there are [issues that are not addressed], for example, we are not sure exactly what happens at school most of the time. Certainly [the 'My World' tool can be combined with current methods], I will hope so anyhow" (participant 16)

"I think there definitely needs to be an alternative method, and I don't even know if there's many psychologists who are terribly comfortable in counselling hearing-impaired people, so I think there's also a lack of understanding on the psychologist's side of understanding hearing loss. Once I was trying to find a psychologist who I could refer a client to, and I think it as quite difficult because there aren't many psychologists who are familiar with working with hearing-impaired people. So I think there may be a gap there as well. I think this tool is one of the better tools I've seen to help with counselling and it could certainly be combined with current methods." (participant 17)

All seven audiologists thought that audiologists, psychologists and Teachers of the Deaf should all address the counselling needs of hearing-impaired children, "as a team process" (participant 12). Participant 13 and 16 also added "speech pathologists [should address counselling needs] as well. I think everybody who has interactions with hearing impaired children needs to talk to them and find out how they're going. Every profession brings something different and has different expertise" (participant 13) and "plus counsellors as I know lots of families need extra support" (participant 15).

3.3.4 Reactions to aspects of the 'My World' tool

The audiologists were asked if they thought that knowledge of psychology counselling skills (e.g. narrative or play therapy) would be useful in using this tool clinically, whereby most of them replied that they thought it would be.

- "Yeah I think so, having background insight would be useful. It might help you get a different thing out of it" (participant 11)
- "Perhaps, but I think for me as an audiologist this tool would be useful to identify issues and refer on. I see it as a referral system" (participant 12)
- "Yes. Maybe for some kids it would open up some feelings that I wouldn't know what to do with. So we need a little bit more background in counselling and psychology and a clearer referral pathway for psychology" (participant 13)

"Yes, but the basics only" (participant 14)

- "It definitely wouldn't hurt" (participant 15)
- "I think some more counselling skills in general would be good. Also having some knowledge on knowing what to do once you've got those issues - so what sort of steps or some pathway to follow to actually get to a resolution or strategy. I guess I'd like more of a process to follow like a coaching model" (participant 17). The audiologists were asked their opinion on whether scenarios on how to use the tool to obtain

certain information (e.g. questions on the summary sheet) would be useful to which they responded:

- "Yeah, videos that are more specific rather than just general as they are now would be fantastic" (participant 11)
- "What I personally would really like is questions to prompt more so, as that to me is really helpful. I find it hard to Figure out exactly what question to ask. This could be done scenario based" (participant 13)
- "Yes, definitely and in a video format" (participant 14)
- "Yes, as it would give you guidelines and how to find out things from the child. I'd prefer this as prompts in a written format" (participant 15)

"Yes that would be great" (participant 16)

"Yes I do" (participant 17).

In response to whether they think that it was clear on how to use the tool as it is currently presented, most of the audiologists said yes it was, however, it was that the videos were very important to giving it that clarity on how to use it.

- "On its own, not the best- it needs to be visually seen in the videos- the box and all the writing just doesn't help you enough" (participant 11)
- "Yeah I don't think it is difficult looking at it on how to use it. I think you would look at perhaps using the questions. You would need to look at the background. You've got to read up on supposedly what the purpose is. I think the purpose needs to be much more clearly identified" (participant 12)

"You could Figure it out, but I don't think you'd get as much from it. Certainly watching the videos, I'm very much a visual person. I like to see it modelled and then I watch it and I can see that I can do that and adapt it to my style. I don't think there's a lot of instruction in the actual box" (participant 13)

"Yes I think it is quite clear" (participant 14)

"Yeah I think so, I can understand how to use it with what has been presented so far" (participant 15)

"I think just with the tools, just what's available on the box, I don't think I'd feel confident with using it. You know I don't know if I'd know how to start it off. So I found that the videos were really important to give me a clear idea of how to approach it" (participant 17).

The audiologists all definitely thought that the tool needed more development and offered ways they thought it could be improved:

- "The idea of it is fairly well developed, however the boards and all that could probably use some tweaking I think it's kind of limiting with the child needing to use their imagination with things that might not look anything like that's in their world. Have an online thing where there's more items to print out and use characters that look more similar to those in the child's world even different boards that look more like their house because you might be spending lots of time with the child saying but that doesn't look like my room, etc. you know. I don't think it makes a difference whether the items are solid or paper/cardboard. I think different packaging for different developmental ages would also be helpful I don't see this [as it looks now] being very relevant to a teenager" (participant 11)
- "I would glue the people into [the stands] as they were fiddly and they come apart. I think you have to have the exact picture of what the child is using, for example the FM system needs to look the ones the kids use here, and the hearing aids need to be exactly specific to what the child has too. So yeah there needs to be more personalisation specific to the child. The hearing aids need to be able to be put on the people, and the use of photos would be really good. I definitely think there needs to be more development of the outdoors area there needs to be more of a typical schoolyard playground and oval there. There should also be room to write specifics like stickers for the child's name and the teacher's name on the people, and the boards, etc. The documents need to be in some sort of organised binder or book. There also needs to be a really good introduction in the book. With the home, I think it would be good to have more of an interactive board, you know, one you could write on and then rub it out" (participant 12)
- "Yeah probably needs more development. Giving us, the people who are going to use it, ideas of how they can use it and what they can get from it in a really straight forward format, I think that is really worthwhile. Certainly you get the idea from what was in there, but I think more in depth stuff, with what you're doing. I'd prefer a booklet for all the information, something that could sit on my shelf. I think the outdoors area could be improved – to me it looks too Scandinavian – it should be a bit more representative of the country you are going to use it in. I'd also really love to see the hearing aids be able to be clipped onto the people" (participant 13)
- "I think the boards are fine in general, because you want it basic to allow the child to invent their world. There needs to be a better representation of an FM system it is not representative of the ones we use here. It would also help to have the hearing aids smaller and able to be placed on the ears of the people. Also there are no bone conductor aids, and a lot of our children have bone conductors aids. I'd like all the information in a booklet form too" (participant 14)
- "Yes, I guess, more different boards would be good or ones you could design to make it more specific to the child, for example classroom and home layout. Maybe having a computer version to manipulate the boards and to be able to print out to personalise it for the child would be good. It would be good to have the hearing aids on the Figure to make it more real, like clip-ons. I guess you could also try more 3D stuff would be best for the little pre-school kiddies would be really good for the figures and boards maybe like a folding book, but the bird's eye view is really good for the primary school aged and up. It would be also really great to have the material [induction pages, and supplementary resources] in a booklet form. The parts of your summary I think should also be included such as the "what are the problems" section and the questions that could be potentially addressed are most important. It was helpful to have the videos with the box for this project too" (participant 15)
- "Yes I do think the tool needs more development. The tool items are okay, but there may need to be more relating to other scenarios, for example sports field items. The tool definitely needs more items for teenagers" (participant 16)
- "Yeah I think it needs to be different for different ages, so I think it's great for primary school age level, but not as appropriate for older children. The concept's still fantastic and I've done a similar thing with adults as far as getting them to actually draw out their lounge room and actually show me where they sit and where the TV is and things like that, so I definitely think there is more scope for the tool. Just having even some basic plans, almost like house plans for older teenagers and for young adults an office plan. These could just be like a line drawing - it doesn't need to be anything fancy. I think that possibly with the having the

hearing aids with Velcro maybe so maybe they could stick them on would be great. Also having the papers in a booklet form with maybe different sections for the different professionals would be good. I think the case histories could also be read at the beginning of the videos would be great too. Yeah I think these questions in your summary are a really good idea to help to just to give the clinician some idea of what questions to ask to get the information they're looking for" (participant 17).

In response to what age they thought would respond well to 'My World' tool to assist hearingimpaired children the 'My World' tool, the audiologists thoughts were quite similar.

- "4-7 years, as long as they've got the language to communicate what they want to say, 8-9 might be a bit old almost and 10 as the upper limit" (participant 11)
- "It depends on language level, it's not really about age by age it's language level and that's often related to hearing loss. I would probably keep to it to primary school, so 6-12 years" (participant 12)

"From maybe 4 or 5 to 10 years. Maybe beyond 10, maybe up to 12" (participant 13)

"Up to maybe I would think high school because when you're a teenager you think this is a little bit too kiddish. But for most of Primary school I think it would suit them. I reckon around 5-12 years, and also anyone older who has the cognitive level of a younger child" (participant 14)

"As it looks now, maybe 3-9 years, however with adaptations for teens I reckon 3 – 17 years" (participant 15)

- "Probably most effective for primary school age, so 6-12 as it is now. It would be great to see a teenage version - this would increase the age range" (participant 16)
- "5-12 years as it currently is presented, possibly to late teens is it also had different packaging for different age groups" (participant 17).

The audiologists gave their opinions on the suggestions for use at different psychosocial stages of development and the functional skills screening tool.

- "[The uses are] okay as guidelines I think, however, background on Erikson's refresher would be helpful. I think you'd need a lot of training [on the functional skills screening tool] to use it accurately and to me this seems much more for psychs than for audiology– there needs to be more direction on how to use it" (participant 11)
- "I think it's good to be thinking in those terms myself (psychosocial stages of development). I like it as a review sheet so it just keeps you thinking clearly. It's a generalized kind of thing. I like looking at characteristics and what is going on. Because you do look at what seven year olds should be doing, what's going on here, are they in this stage? I like the ideas of other resources to use it with. I liked [the functional skills screening tool] a lot, although a lot of this information we gather in other ways, but its great" (participant 12)
- "I think it's good that they've got here [on the suggestion for use page] what you can except from communication from the different ages. To be honest, as an audiologist, [the functional skills screening tool is] quite daunting. I didn't know how to start reading it" (participant 13)
- "[The uses at different stages of psychosocial development] looks like a good guide and a good place to start. [The functional skills screening tool] is probably a little bit beyond our scope, because we haven't had the training to really make comment on other areas. We would need training and I don't know if that's appropriate for our current field of work because it looks more like child/educational psychologist tool" (participant 14)
- "[The uses for different stages of psychosocial development] is a good guide more than anything.
- For the functional skills screening tool, I think you'd need a lot of information from a lot of different professionals, so it needs a multidisciplinary approach" (participant 15)
- "There is some good information and guidelines on the uses for different psychosocial stage of development sheet. The use of the functional skills screening tool is probably specific to educational audiologists, although some knowledge by all is needed too" (participant 16)
- "I don't know if there's enough information on here to actually sort of understand how and why you'd use the tool for different stages. I think it would also be good to have a video example of each age group to demonstrate this and show what sort of information what sort of information that you're trying to get from that age level. I did feel that I didn't think audiologists really had enough information on most of these areas [on the functional skills screening tool] to be able to rate the child, so even more background or have more input from other professionals. So it needs a multidisciplinary input into it, rather than just audiologists" (participant 17).

All of the audiologists felt that the tool should be used by audiologists, psychologists and Teachers of the Deaf. Other professionals suggested included speech pathologist by participant 11, counsellors and occupational therapists by participant 15, and parents by participant 16. When asked what they thought the tool should be used for by audiologists, responses included:

- "Counselling on hearing strategies and counselling on parent interaction with the child. I could also see a use for the hearing impaired child and their friends – i.e. teaching them as a pair/group" (participant 11)
- "Audiologists as a screener for referral, we could use it as a supplement to other materials we have. Educational audiologists could use it more for hearing strategies. They should only identify that a concern [in social-emotional wellbeing] exists and then refer this to a psychologist" (participant 12)
- "Strategies counselling, an educational thing for parents and behaviour modelling" (participant 13)
- "In terms of us using the tool it would mainly be gauging any other situational areas where we can teach the child to use their devices more effectively. Hearing strategies, what happens at homes that causes difficulty or what happens at school that causes them difficulty and open up areas where we can suggest FMs and assistive listening devices" (participant 14)
- "Hearing strategies, as it appears now, not really for screening and referral I think checklists are a more appropriate tool or format for this. The psychologists should be the ones using this tool to look at social and emotional aspects with the child" (participant 15)
- "I think it should be integrated into the rehabilitation program to enhance aiding and communication *strategies*" (participant 16)
- "Counselling on hearing strategies, and also to give us an indication of what technology they might need. I think we don't really have a good concept on when we should be referring on for more psychological input, so screening and referral could potentially be a secondary use. I think it would, might help uncover some emotional issues that maybe the parents hadn't been aware of before as well" (participant 17).
- The audiologists thought that other professionals could use it for specific things too, such as:
- "Teachers of the Deaf could use it for classroom and behaviour modelling. Psychologist should definitely use the tool for behaviour modelling" (participant 13)
- "I can definitely see psychologists using it to investigate more of with emotional aspects of the hearing loss and how children can manage those emotional reactions, behaviours, and I think definitely Teachers the Deaf could use it as well to help the child manage their own, teach them to manage their own needs in the classroom and things like that" (participant 17)
- Other uses that one of the audiologists suggested that the tool could be used for included:
- "I could see the tool being adapted for lots of different things, not just for hearing loss but for other disabilities as well, of course it would need to be changed and modified depending on what the, you know, disability was, but I think in a chronic, you know, lifelong disability that a person has to live with and has to manage then yeah I think it could be useful or lots of things. I think in goal setting that's also where I'd find it really, really useful to actually establish, and to help the child establish I guess their own goals, or us finding out from the child's perspective what's important for them" (participant 17).

Audiologists were asked to give their opinion on when and what circumstances should the 'My World' tool should be used, whereby most thought it should be used annually or periodically.

- "I don't think candidacy, I think it needs to be a post rehab thing, I don't think it needs to be set every three months or every review, just whenever you are looking for specific information and you think that counselling is required" (participant 11)
- "Probably to check on the FM system use, probably educational or annual assessments. Not for cochlear implantation assessments as there's already too much going on, so not till after they've been implanted. I wouldn't use it all the time. I would see it as just another tool I could use in my repertoire when need be in situations where it's needed. This needs to be used by someone who sees the child on a regular basis, so most likely the visiting teachers would be the best person to use it the most" (participant 12)
- "I think it has applications for lots of different things. The annual review, if you have a child who doesn't sort of open up as easily as others. We generally see kids once a year once everything is stable, so I think periodic education counselling, I think that would be really good. I think we can see kids more, we are under our average hours of what we're meant to see children. So perhaps that would be a really good way to do periodic counselling if they wanted to come for that" (participant 13)
- "I think the child needs to be a consistent [amplification] user before they can really give you meaningful advice or feedback, because if they're not consistently using their device and they're having difficulty, it's probably

because they're not using their device. So I think you have to establish that they're a good consistent user before this tool can be effective. I think [it should only be used] when it's necessary, because it might not be appropriate to do it at every review. At the moment implant agencies are going to look at audiological results rather than something the 'My World' tool might offer, so probably not for cochlear implant candidacy" (participant 14)

- "Definitely at periodic educational assessments, and at intake or review appointments" (participant 15)
- "The 'My World' tool should be used if there is a problem (e.g. at school/home), but also for annual review or periodic reviews" (participant 16)
- "I think it needs to be done periodically. It should certainly be done at the beginning of a program for a child to actually look the child's needs from their perspective, and then probably just being looked at the end of the program. For some children the program can be quite long, can last over twelve months so I think once you've set the goals up there needs to be some way of evaluating those goals and to see if they're been met. So it could be used again to see if those goals have been met" (participant 17).

Some of the audiologists thought that documentation form could be improved also.

- "If you're going to use it ongoing, maybe more of a booklet style to track progress rather than a one off thing" (participant 11)
- "I would like to see more of an action plan, there also needs to be a psychologist added to the list of professionals there. It needs to be a bit more specific and not so open ended. I think it would be better to have each agency make their own up, rather than using this one" (participant 12)
- "I guess it needs to be fairly generic because the tool has so many uses, however it would be nice to have it all on one page. I would also like a question to be included on what situation you have modelled" (participant 13)
- "I think this is probably user friendly enough for us to adapt. Maybe a bit about the technical side for what changes we did to their devices or what devices were recommended as a result of doing the 'My World' tool" (participant 14)
- "I did think it was a bit vague. I know from working with audiologists, and developing their skills, that some prefer a lot more structure in forms, so it probably needs more structure. I think it needs some sort of documentation about why they are doing, why they were using the tool in the first place, whether it was for goal setting or to investigate an issue, or look at counselling, so somewhere work can be documented, the reason, why they did it. There also needs to be an evaluation, that is, after [the decisions have] been implemented, what was the outcome for the child" (participant 17).

Further comments on the supporting documents by the audiologists included:

- "I think having the sample questions is really helpful. I think over time the audiologists using it will formulate their own questions, but these questions here are a good starter" (participant 14)
- "The idea of a booklet of this information with a contents would be fantastic and having a quick reference guide would be good" (participant 15)
- "I think I would like more information about adapting it for teenagers or young adults, because there wasn't an awful lot about that there. Maybe an expansion on the pitfalls to avoid would be good also" (participant 17).

Audiologists were asked whether they would you use the tool clinically as it is currently presented, and why or why not. They mostly answered that they would or would try to, and their reason varied, mainly because of the clinic environment.

- "I'd give it a go. I think you have to judge the kid you want to use it on, use it on those kids who you think would be into it, so not everyone. My reservations would be only of it is not appropriate or they are too young – not those who can't properly communicate back or older teens. Here [at not-for-profit educational institution] we're not bound to you know 1 hour for them and that's it, you know we see them regularly, so there's not as much of time constraint – we are very lucky" (participant 11)
- "Perhaps, not on lots of children though, but I would prefer it to be more personalised before I went ahead and used it, and this would be my cause of hesitation to use it, as there are barriers that make it from having an effective use. It would only work for kids who are okay with generalising as it is now" (participant 12)
- "Yeah I probably would. I'd like to try it, but it's really just finding the time and actually how you practice. It's probably just a matter of practicing with some kids and see how it goes. I guess I would worry that I'd run behind...Anything new disrupts your routine. Once you get into it usually fine, but it's hard to start it" (participant 13)

- "I would use the tool, but the greatest barrier for us is time. Because we have so many audiology items we need to check at each review and reporting, and sometimes extraneous things like this [tool] just get put on the backburner" (participant 14)
- "Yeah I would, why not. You can get a lot out of it in its current format" (participant 15)
- "Yes I would use, but perhaps on a smaller scale due to time constraints" (participant 16)
- "I would certainly use the tool; I probably wouldn't use it for all children just because of time restrictions in the clinic though. I would use it with those children where I felt they didn't really understand their environments or their needs. I know this is not what the tool is designed to do if we want to try and incorporate the child's perspective more into our rehab and therefore in theory we should be using it with all children" (participant 17).

Most of the audiologists thought there was a use for the 'My World' tool and that it was necessary and helpful, but many could also see issues with it being used.

- "Yeah there is a use but again it comes down to time, I don't know how many people could. Some issues I see may be - at most it just won't work like you would do it and you wouldn't get anything out of it but no harm will be done so" (participant 11)
- "Yes, but in some, not all. It is just one of many tools you could use. I think you need to have mentoring with using the tool. In terms of issues - you need to be very clear with what your goal is with this, and you need to be clear what your own boundaries are as an audiologist, for when you need to stop and when you need to refer on" (participant 12)
- "Yeah there is a use for it. I would say there is a need for it, say if you look at that Kathleen story, it just highlights that things can go on and on and on for years and years and no underlying issues are addressed. If it opens up like a Pandora's Box of other issues, if the child is being mistreated at home or school. If that opens up, what do we do with that information? I guess that's the danger of using the tool" (participant 14)
- "Yeah, definitely there is a use for it. The only thing I can think of in terms of issues would be time constraints and this could be a problem at different clinics where they see clients back to back, and would be struggling to include something like this is their sessions" (participant 15)
- "Yes, but at specified times and not always. It is useful but I think there may be issues with disclosure and privacy" (participant 16)
- "Yes, I do. I think it would be really helpful. I think one of the biggest issues of introducing anything new into the clinic is that people just need to have a go, and that's you know got to overcome that sort of reluctance for people to have a go at using it" (participant 17).

Some of the audiologists felt that parents could have a role in the use of this tool either observation only, or observation and actually using the tool with their child.

- "Have them use it after watching you use it a few times switched on parents would probably get the idea with real life guidelines" (participant 11)
- "Yep, definitely for observation, but for use I think it depends on the parent and their comfort level and being able to talk about the child's hearing loss with their child [if they were to use it]. I would certainly offer it to parent though. I think some will take it up and others wouldn't like the idea. It would be interesting to hear what parents would think after using it" (participant 12)
- "Yeah I think they could use it they could model the school situation and it would give the parent a bit of info at how they're coping at school" (participant 13)
- "Yeah, I think they could use it, but with parents they've got to be quite careful what questions they ask. They can be quite leading, so it takes a rather neutral parent to use this properly" (participant 14)
- "Yes I think perhaps, at least observation would be fantastic. There would only some parents who I think would actually want to use it themselves though" (participant 15)
- "Yes, I think use and observation it would be a good tool to talk about hearing in the family home and so the parents can see where their child has difficulties" (participant 16)
- "I think it would be fantastic for parents to watch, and I also think it would be really good for them to use, and I don't think they would need a lot of instruction. I think if they were to see how the clinician uses it first would be a good modelling exercise" (participant 17).

Most of the audiologists felt that the 'My World' tool could enhance/improve the outcomes of paediatric rehabilitation:

- "Yeah I think any information gained out of a kid that helps them feel better and you know and the parent knows more about the child, it also might promote use of FM or make you realise you need to raise the gain or something or anything would be beneficial - at worst you've just lost a bit of time" (participant 11)
- "I think again it's a tool, and it's one of many so certainly it's not going to make it worse, although it may point out some things and it may not, so potentially maybe or maybe not" (participant 12)
- "Yeah, definitely. As I said, I think communication is key in successful rehab and getting people to advocate for themselves and to learn those skills. I think this could definitely help that and it could teach kids in a more fun way and non-threatening manner that it's okay to have feelings about these things and that you could model various behaviours and stuff like that" (participant 13)
- "Yes, especially if it opens up areas where we can offer additional assistance, whether it be improving the current device, or offering additional devices. Or getting on-board with other professionals to help the child, or helping the parents to see things differently and offer support in other ways" (participant 14)

"Yes I think so, for sure, as this is information you might not get otherwise" (participant 15)

"Yes, as you obtain more emotional and communication information" (participant 16)

"Yeah I think it could, I think the really important thing for rehab is to make sure that what we are doing is relevant for the child. And if the child feels that they've had some input and that it's relevant for them then I think we might have much greater compliance with using devices or using strategies" (participant 17).

The audiologists were questioned on whether they thought the 'My World' tool would be useful for obtaining both the child's perspective of their hearing loss and helping the child. The overall response was yes to both.

- "Yeah it could do, it totally depends on how you then talk back to them and how good you are with saying how about you do this instead and then they'll get benefit out of it. If you're just saying oh okay that's interesting then then you're just going to get one side of it and they're not going to learn. You have to take what they say and respond in the correct way for them to learn" (participant 11)
- "I think it's a long term think, and I don't think you'll get that all out of one tool in terms of obtaining the child's perspective of their hearing loss. I think it is really good for helping the child though in terms of that pathway along self-advocacy" (participant 12)
- "Yeah, definitely" (participant 13)
- "Yeah, I think so, I think if you give the child a voice it helps not only with their self-esteem but with their confidence as well. Once you have that information you can recruit people to help this child for their particular needs" (participant 14)
- "Yeah, definitely" (participant 15 and 16)
- "Yes absolutely both. I think it leads quite nicely into the child discovering their own strategies of what they can do in different situations. So rather than the clinician telling them, well what you can do in this situation is XYZ, the child can actually discover that for themselves" (participant 17).

Additional skills or resources that the audiologists felt could enhance the use of this tool in the rehabilitation of hearing-impaired children included:

- "Some more background psych info and on child development and things like that. A booklet for form for the supporting resources would be good as it's a bit all over the place. Possibly a booklet for each professional and then you could extract information more specific to your needs. More demonstration videos on HOW to use it" (participant 11)
- "A mentoring process [for professionals]. It might be useful having the students mentored on talking about these things as well" (participant 12)
- "A training session on using [the tool]. I really liked those videos on modelling behaviour. There also needs to be a really succinct summary with questions to prompt, and a good documentation form, one that we could hopefully type into" (participant 13)

"Different formats for different learning styles would help with this tool I think" (participant 14)

- *"There needs to be hands on prac, and use of mentoring in learning how and when to use the tool"* (participant 15)
- "There needs to be defined training, role playing and learning narrative techniques" (participant 16).

Questions that the audiologists thought could also potentially be addressed by using the tool in addition to those in the summary form included:

"How does the child feel about their hearing aids?" (participant 13)

"Does the child have self-awareness of their hearing loss?"

"Is the child confident to talk about their hearing loss?"

- "Does the child have the knowledge of management of on their own in an environment?"
- "Does the child have an awareness of the limitations and benefits of their amplification?"
- "Does the child understand how to use their new technology correctly? E.g. hearing aids/FM systems"
- "What is the child's level of family involvement in rehabilitation?" (participant 16)
- "What does the child understand about their hearing loss?" (participant 17).

3.4 Teacher of the Deaf interviews

3.4.1 Reactions to the 'My World' tool and current methods of obtaining and evaluating information from the child's perspective

The first reactions to the 'My World' tool by the Teachers of the Deaf were:

"It's nice and compact, seemed like there was lots of instruction and it seemed simple" (participant 18)

- "I was quite interested to have a go at it. Wow that's great to see how they [the kids] are going and how that helps me" (participant 19)
- "Initially, I was a bit sceptical, and wasn't sure what it would offer me more over than what I already have. I thought with all the resources we had we covered most things. When I looked at it, I thought it was quite basic, but then you forget that it's the kid's imagination that brings the tool to life. Since I've now looked at everything, I think it's amazing how the children take it on and can explain what is happening in their world, and they get really involved with it" (participant 20).

In responses to comments by audiologists to the tool from '...it's the best innovation I've seen for years in paediatric rehabilitation...' to '...without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain...' the Teachers of the Deaf responded:

- "I can understand some people being sceptical and the role of the audiologist seems quite clinical, whereas this pathway of going down and spending a lot of time role playing and talking with the child is probably not the norm for most audiologists" (participant 18)
- "From an audiologists perspective that may very well be true, I guess it depends on where they're at and the processes of working out where a child's at. From a Teacher of the Deaf perspective, it actually gave me a really good insight and the other goals that we have to achieve I think it works with a child who is having difficulty in the classroom, it may provide us with some excellent information to be able to support them to achieve their goals. So sometimes I think you need to take a step back and actually implement some different things in order to achieve the goal at the end. It also depends on the type of audiologists you are dealing with" (participant 19)
- "I think everything at the moment is time, and think people get so wrapped up in trying to look at everything they have to get into a child's rehabilitation, when actually what's really important is what the child sees as being important, and not what we focus on as being important. So the second comment is very adult minded" (participant 20).

The Teachers of the Deaf have a very similar approach to the audiologists in obtaining information from the child's perspective of their hearing loss and evaluating how well a hearing impaired child is managing to go about his or her daily life with hearing loss, at home, at school and in social situations.

- "A lot of the time it's through observation [in the classroom] and questioning to see what's happening, so we observe their coping strategies and then talk about them when we've got concerns. We also talk about outside of school as well, we talk about out in the playground, we talk about things that are happening at home, and we'll talk about things they do recreationally. So if it's a sport or if they go to the movies, so we talk about different environments" (participant 18)
- "Generally through informal discussion or observation to see how they interact within a classroom or from what the teacher has said. Not a whole lot of interaction with parents to obtain information. If there is issue at home they will be discussed and possible courses of action, but our focus is more on classroom issues" and "Checklists for the teacher and the student can do a questionnaire themselves for us to see how they feel they're coping.

There is also a hybrid questionnaire to keep track of hearing aid use and choice of seating positions in the classroom. We also use the TEACH questionnaire, and an audiological management checklist" (participant 19)

"No there's no formal evaluation of things or questionnaires. It's usually informal discussions most of the time" (participant 20).

3.4.2 Reactions to the 'My World' tool videos

In regards to the instructional video, two of the Teachers of the Deaf found it useful as an introduction to the tool, and the other thought it wasn't useful and provided a way that it could be improved.

- "I thought there was plenty of information there. You have to give the professional some credibility that they can pick up a tool and interpret it themselves and apply it to their own work environment, whether they are an audiologist or a Teacher of the Deaf" (participant 18)
- "It was okay and was a good introduction for something that I'd never seen before but I wouldn't say it was overly useful for the tool itself" (participant 19)
- "I think I got more out of the other videos with the tool being used. I found it to be very dry. I could have got all that information from the written material provided. I don't think this video is very necessary, but it could be improved by giving examples on how to use the tool, or to give possible ideas as snipetts during the videos of the tool in use to highlight the important the aspects" (participant 20).

When shown the Kathleen and her family video, the reception was quite positive on how it related to the tool and/or its use:

- "I don't know if it showed the need for this tool but it certainly showed the need for parent education. I think [the tool] is a non-threatening way that parents could be educated about how their child's coping at home" (participant 18)
- "Yes it did highlight a need for the tool and it gave some interesting insight" (participant 19). The Teachers of the Deaf really enjoyed the videos of the tool in use:
- "Yeah I thought they were good and it was nice to see different audiologists using it and children with different levels of hearing loss and abilities using the tool. I thought they were really good. I don't think there'd be a lot of difference [if we saw examples of Teachers of the Deaf using the tool], I think it's very similar to the way we'd use it the same way to find information" (participant 18)
- "Yeah, it definitely highlighted a need for this tool. It was an eye opener for sure, as to the child's perspective of the world, and that what is actually happening is nothing like what we expected. It especially highlighted the need to watch the ones who are academically bright in some cases, as they can usually appear as though they are coping okay" (participant 20).

They also strongly thought that the tool did allow the audiologists to obtain meaningful information about the child's perspective of their hearing loss:

- "Yes I think that they got the information that they needed and to check up on if they were using the equipment like their FM, where they were wearing their hearing aids and they situations they were finding it difficult to hear in" (participant 18)
- "I do and I think that's because I've had a go at it myself, and knowing the children I've used it with I know there were light bulb moments for me. So I can only assume that an audiologist who knows the child they are working with could get those light bulb moments too. It wasn't ground breaking and not every single thing was like wow that's amazing, but there were certain things with certain students that I went oh wow I never thought about that" (participant 19)
- "Yeah I do, yeah. The idea of things being able to obtain information on what they do every day and how they feel about them is really insightful to the professional" (participant 20).

Other comments on the videos by the Teachers of the Deaf included:

- "I think it's got the potential for a lot more use in the current field, and I think there could be lots of issues raised with it, for example, bullying and some of the relationship building of the children and also was wondering with the style of it if the child made a disclosure to the audiologist, I don't know if the audiologists are trained or prepared on how to manage that. i.e. mandatory reporting and the state legislation on that" (participant 18)
- "It was good to see how other people have implemented this tool. It was good to see the reactions of the children as it made me wonder how that could relate to the children I see and the behaviours that that child is behaving is for the same reasons for my students– this was the biggest benefit of these videos I

think. It would possibly be good to see a video on a Teacher of the Deaf using the tool, but you might see a similar outcome. I think it would be good to have some instruction into those videos of the tool in use so when you get to a certain point it stops and you go blah blah blah as so to have some more direction, so in terms of perhaps having a directional video perhaps use these videos you already have to provide or create an instructional video" So in constructive criticism, more direction is needed in the videos on how to use the tool" (participant 19)

"What surprised me was the fact that those children had very good language, so I wondered if they had been specifically picked for using the tool with for the videos, because I know some of the kids I see don't have that kind of vocabulary at those ages. I think it would be good to see video examples where the child is not so willing or does not have as good vocabulary to see how the questioning and answering would go with using the tool with those kinds of children. I'd also like to see an example of it being used with a signing interpreter with a child who uses AUSLAN" (participant 20).

3.4.3 Paediatric rehabilitation and counselling skills

In response to what extent do you feel that counselling hearing-impaired children should be within the scope of Teacher of the Deaf practice, the Teachers of the Deaf felt that a counselling role fell to them quite a bit.

- "Counselling is a huge role of the Teacher of the Deaf, but it really needs to be supported with psychologists" (participant 18)
- "It falls to us quite a bit, as we are the ones that usually have the most contact with the hearing-impaired kids. I think there need to be greater services from other professionals but if that's not the case then I think we need greater training in the area, and to have that as part of our scope of what we actually do, as you have to treat the whole child" (participant 19)
- "I can see it from two angles. When I did visiting Teacher of the Deaf work, did I get a chance to do it not really. Should it be in your training – yes, because it's one of those things that doesn't get covered elsewhere. Communication in our course is such a big part that the other stuff [like counselling] gets forgotten. Now being a permanent Teacher of the Deaf at a school, I can cover some of it and it's a more multidisciplinary approach here for the child with the psychologists and audiologists also" (participant 20).

The Teachers of the Deaf had a very holistic approach to the use of family and patient-centred care in respects to the child's rehabilitation, and what the 'My World' tool could offer.

- "Yes I think it [the 'My World' tool] brings in the child's perspective, which is easy to overlook when you are in an appointment or something, as it's very focused on the equipment. So yes it is nice to have that child focus" (participant 18)
- "I think we need to marry the two because I think that children even from a very young age a child should know when things aren't going right and it's just about having the ability to express that. I think as adults we make decision about what's best for a child but I think sometimes actually the child knows what's going to be best for them. I don't think that's always the case but there have been several instances where the child's saying there's something wrong, there's something wrong and at the end of the day the child has been right. So I think the two approaches are important and should not be just one or the other. I think the sooner the child can have a say the better, so yeah I think the tool could help with bringing in patientcentred care in earlier" (participant 19)
- "I think they are compatible and they go hand-in-hand it is not a switch at a particular age. I think this tool could bring in patient-centred care earlier, yes" (participant 20).

In terms of counselling hearing-impaired children using a tool in their rehabilitation, two of the Teachers of the Deaf responded that they would feel comfortable with one saying only if she "received appropriate training to do so" (participant 19). Participant 20 said no "because I have limited experience. I suppose it's also practice over time also. I would be worried I wouldn't get the information I wanted." (participant 20).

All three Teacher of the Deaf participants felt that to some degree that they did perceive a gap between the counselling by a Teacher of the Deaf, audiologist and a psychologist. They also voiced their opinion on whether they thought this tool would be successful for bridging the gap between the roles of these professionals.

- "There's a huge difference, yeah. I don't know how much counselling training audiologists actually do, um, and I think appointments often have very strong time constraints and sometimes counselling happens incidentally. So to have an appointment where you have to go to a particular place or an office or something it's often not the place where a child would talk, particularly if there were other people around, and audiology appointments are, um, much more equipment focused. If professionals could use this tool effectively it could potentially [bridge this gap]" (participant 18)
- "I think we give a fairly reactionary approach to supporting kids, but there are children who fall through the gaps and appear to be coping okay and there are other children or for example those who come to the realisation in their teens that they are not going to 'grow' out of their hearing loss, so clearly there is a gap somewhere, but I don't think that occurs for all children, and sometimes it's impossible to catch everybody and this makes it difficult" (participant 19)
- "There has to be communication [between the professionals], and if this doesn't happen, yes I do. I think this gap in less in multidisciplinary approaches and centres that cater for the [hearing-impaired] child. Even with such a set-up, there are still things that are missed, especially if you look at the government multidisciplinary approach due to caseloads, and limited time. The tool could potentially play a role [in bridging this gap]" (participant 20).

In response to being asked whether they felt that they had a good understanding of hearing loss from the child's perspective or whether they felt this was a 'gap' in helping hearing-impaired children, participant 18 felt that she did have a good understanding. Participant 19 had a different broader and holistic view of things and participant 20 felt she did not have a good understanding.

- "I think I have a reasonable understanding, but unless you walk a mile in someone else's shoes you can never truly understand, so perhaps then there is a gap, but I think I am open enough to listen to the students that I work with and to try as best as possible to see it from their point of view" (participant 19)
- "No I don't, because I'm not them, and my perception is not their perception, and so this is definitely a gap. My priorities are not their priorities. At the end of the day I've got work to mark and reports to write, and that's my priority but their priorities are: do they have a good group of friends and do they understand what's going on and do they understand why someone's not happy with them so that's their world, not mine. I do think this tool would help me to get their perspective of their world much more than I currently do" (participant 20).

In response to being asked which professionals (Teacher of the Deaf. audiologist, psychologist, all or selected) should cover the scope of counselling hearing-impaired children, two of the Teachers of the Deaf felt it should be covered by all, and one thought it should be mainly within the scope of a Teacher of the Deaf and a psychologist.

- "Just in my experience, I haven't come across many audiologists that do any counselling at all, the appointments seem very driven by the equipment and they talk about where it can be used, but I think there is usually not enough follow up, and I think that the Teachers of the Deaf do all of the follow up, so I think it's more Teacher of the Deaf and psych scope" (participant 18)
- "I think everybody needs to play a role in supporting the counselling needs of the child, but I think psychologists need to take the lead. However when there's a limitation with the number of specialist psychologists for all the students I think as a default it comes back to Teachers of the Deaf and school psychologists to provide that support. I think it would be great if these children had more psych support" (participant 19)
- "I think it should be there from all of these [professionals], but mainly from a psychologist for the socialemotional aspect" (participant 20).

Participant 19 and 20 responded that they had both received some teaching on Erikson's stages of psychosocial development and Jean Piaget's theory of intellectual and perceptual development in their teaching degrees, but that "no I don't know how they relate to the psychosocial features of hearingimpaired children. I would like to know more about these and how they do relate" (participant 19). Participant 18 had no knowledge of either of these. All three Teachers of the Deaf expressed that they would like more teaching and training on counselling and psychology. Participant 18 commented that "in Teacher of the Deaf training there was a bit on counselling, but it was more on dealing with grief and the grief cycle and helping parents move through that process, so it was very focused on the family. There was nothing specific on [teaching us in] counselling children" (participant 18). The Teachers of the Deaf were also asked on whether they feel there needed to be an alternative method for the counselling of hearing-impaired children or if they feel current methods were effective, including what, if any, issues were not addressed with current methods, and if the 'My World' tool could be combined with current methods. Their responses included:

- "Depends, like some of the psychologists they use quite formalised assessments tools whereas others are much informal, but where there is counselling we [Teachers of the Deaf] are usually not there, it's done privately and then we would discuss it with the pysch afterwards but there is some confidentiality factor and it's important that they withhold that. I don't think here [non-for-profit institution] there are issues that aren't addressed; I think it is really well covered. In other work environments a lot of it isn't covered and a lot of it falls onto the Teacher [of the Deaf]. Oh yeah the tool definitely could be combined with current methods" (participant 18)
- "Depends, I think the current methods are effective for some children who just sail through but then there are others who for whatever reason they just seem to struggle, and so for those children yes I do think there needs to be alternative methods. So yeah it really depends on the child. I think that the 'My World' tool could potentially be combined with current methods and it could potential provide professionals with being able to find the information they are looking for" (participant 19)
- "I don't really know what the current methods are that are used, so maybe. Yes, definitely I think the 'My World' tool could be combined with current methods. There is definitely a scope for it" (participant 20).

3.4.4 Reactions to aspects of the 'My World' tool

All three Teachers of the Deaf felt that knowledge of psychology counselling skills (e.g. narrative or play therapy) would be useful in using this tool clinically.

"I think it's essential, particularly if there is any disclosure - you need to know what to do. The tool is just a tool, the right people just need to pick it up and run with it. You don't need the counselling tools within it [the box], it needs to be training in these areas in the professional background rather than on the tool per se" (participant 18)

"Yeah I do, especially if you are going to implement it wholly" (participant 19)

"I do, yes. I think I would feel better prepared, because what if you get an answer you don't know what to follow on to, and how to answer questions that you might not be able to as easily cope with or be prepared for without otherwise" (participant 20).

Participants 19 and 20 felt that it would be great if there were scenarios given on who to use the tool to obtain certain information (such as the questions in the summary sheet). Participant 20 thought "I think this would be good to have in a flash card format for questions and information for using the tool for a specific reason such as one of these questions. This could be done for each section of professionals" (participant 20). Participant 18 felt that the example videos were plenty.

All three Teachers of the Deaf thought that it was clear on how to use the tool as it is currently presented, although participant 19 also additionally commented, "*I think the tool is one that you need time to look at and read about before going to use it though. With really good instruction you might get there quicker with using the tool to its full extent*" (participant 19).

They also all thought that the tool could be developed more from the current format.

- "The only thing I was thinking when I was looking at it is the people you know, maybe some different cultures and more people. I'd love all the supporting documents in a booklet form" (participant 18)
- "I think there needs to be more home items and more environmental things. The figures themselves actually need to be a bit sturdier as they can easily fall over or children can bend them because they are not solid. I think thicker cardboard would be good or 3D format. I think the packaging looks great at it is. I actually had a go at using this with a student of mine, and I asked him what he thought of the people and he said that the people need to look a bit prettier. He also told me that he'd like a 'middle' face, so one of those emotions in between happy and sad, and yeah I agree that there need to be more emotion items. A booklet form would be good for all the information provided including the supplementary documents and your summary – I think if you just had all the generic information at the start and then had different sections or appendices for more in depth information for the different professionals that would be good" (participant 19)

"Yeah, I think the items could be added to take in a few more thing of our developing world such as iPads. I think the 2D form is fine – if you start putting it into 3D form it would be good for handling but then it would become bigger and it would be this thing that would take up your whole shelf. I like how it is compact, and I like the multi-diversity of the people, however I think there needs to be a baby Figure, you know for baby siblings, as I know some hearing-impaired kids have trouble and get frustrated with hearing babies crying. There needs to also be something that makes it more personal, and so the child will give you the true information. Maybe a different version of an FM system would be good also, and having the hearing aids to be able to be smaller so they can be clipped to the people, so it's more real to them. I think using photos would make the session less spontaneous. I would love a booklet form of all the information and this should be fine for all the professionals and to then read the bits that applies to each one" (participant 20).

In response to what age they thought is most appropriate for the 'My World' tool, and whether they thought the packaging needed to be different for different age groups, the Teachers of the Deaf reported:

- "I don't think age is the issue, I think it's the language level. You need someone with a level of communication of a 5 year old and upwards. You need the intellectual and language ability of about 5 years and up. Not really, I think that it is fine the way it is and that it is compact and easy to store" (participant 18)
- "I think it is okay for primary school age, but yeah I think there needs to be a different version if you are going to use something like this for teens, so yeah different packaging would be good. The current tool would be good for 5-12 years, and the tool would be fine to have the same packaging for these ages. If there was a teen adaptation possibly up to 18 years I think, depending on the teen" (participant 19)
- "From 4-15 years. I think it would be really good to have different versions for different age groups. The idea and the concepts [of the tool] are fantastic but I think it would allow more scope with variations, especially for older teens." (participant 20)

The Teachers of the Deaf were also asked what their opinion on the suggestions for use at different psychosocial stages of development and the functional skills screening tool in the supplementary resources. Their responses were as follows:

- "I thought the suggestions [for use at different psychosocial stages of development] were fine, it was good. I think it could help with using the tool. I really liked it [the functional skills screening tool], it was really broad and it gave a really good overall picture of the child. I was really interested in it, as I hadn't seen one like this for hearing-impaired children before" (participant 18)
- "Yes I thought [the suggestions] were helpful, especially the activities and additional resources section. It definitely gives people a really good starting point for how to use the tool for different developmental ages. [The functional skills screening tool] would certainly be something that could be used really well in a multi-disciplinary team to give a holistic overview of the child" (participant 19)
- "[The suggestions] are not specific but a good start as an overview. I don't like the classifications for the child by age. I think [the functional skills screening tool] is a very multi-disciplinary tool and would require many professionals input but I can't see how it directly relates to the 'My World' tool though. It is a good holistic checklist though." (participant 20)

Participant 19 and 20 felt that the 'My World' tool should definitely be used by audiologists, psychologists and Teachers of the Deaf. Participant 18 responded, "I think psychologists and Teachers of the Deaf definitely, but audiologists only if they were good at talking to the children and knew how to counsel children – you know, really get down to the children's level. I have met audiologists who would not be able to do that. I think it would have more use with an educational audiologist rather than a clinical audiologist. I also think a classroom teacher and a speech therapist could also use it as a teaching tool." (participant 18)

They also gave their opinion on what they thought the tool should be used for by Teachers of the Deaf:

- "Mostly for counselling on hearing strategies and also working with the children on what personal strategies they need and where their breakdown is" (participant 18)
- "Screening and referral to a psych, counselling on hearing strategies and counselling on social-emotional wellbeing, all of these" (participant 19)

- "I think for a spontaneous session, for example, if something has happened in class or behaviour-wise. I think it's good to use to follow up on information like this, and also to counsel on hearing strategies to give the child other options on how to cope with difficult situations. I think we could also use it for as a screening tool to refer to psychs and also counselling on social-emotional wellbeing of course" (participant 20). Other alternative uses were also suggested:
- "You could also use it as an everyday teaching tool, especially with the younger children" (participant 18)
- "I find with the [hearing-impaired] kids that I see in that there are problems in regards to their memory more than kids without a hearing-impairment. For example, when I speak to them about what did you do last night or what did you do in class this morning, they have lots of trouble remembering. So, I think this could be a really good visual tool that could also be used for explaining and helping the kids to picture and help with their recall memory. Maybe to also help the children improve their vocabulary and expand it, for example different word but similar meaning such as light vs. lamp"
- (participant 20).

In response to when and what circumstances the 'My World' tool should be used The Teachers of the Deaf said:

- "I'd probably use it once a year to touch base with the children on how they're going in the classroom. I think audiologists should use it only once a year also, you don't want to use it more than that otherwise they become too familiar with it" (participant 18)
- "I think you could use it when you first meet a child to build rapport with them, I think it would be useful to get that initial reaction to obtain their world, and then in other instances when things just aren't going right, and you can use it as a diagnostic and a goal-setting tool. The amount of use would probably depend on the child, so in some instances you might only use it once, so really on an as need basis" (participant 19)
- "When there has been an incident that needs to be discussed more to obtain spontaneous information about the problem and to offer education to the child on that situation. If I would use it I would use it for a block of targets depending on the which target, for example a social-emotional, an educational, an audition, a language/speech target, and then use it to revisit those targets, so I'd probably use it a couple of times a term for two weeks" (participant 20).

All three Teachers of the Deaf commented on how the documentation form could be improved:

"I think the questions are fine, I would just be looking for more room to write" (participant 18)

- "I found that if you are going to set goals and strategies it's a great form but it depends on the agenda for using the tool, so if it's going to be perspective based, goals and strategies then maybe not so much. I think I'd like something a bit more basic like – challenging and good environments to listen in and then maybe strategies the child uses and further strategies discussed" (participant 19)
- "I would say it is okay, but not the best. I'd prefer a chart I'd like to see things I could monitor to see if things have improved over time. You know to see what the problem was, what the agreed strategies were, and what the outcome was later on." (participant 20)

They also commented on the supporting documents:

- "I think the supporting documents were definitely necessary to be included with the tool. I thought the videos were really good, I'd prefer them to be in the tool's box rather than on the web, or as well. It's always really good seeing someone using the tool to get an idea of how it's used and to help you see how you would use it yourself" (participant 18)
- "I think the tool would have been really hard to use without the supporting documents. There definitely needs to be that kind of guidance here, so I thought they were pretty good. The questions were a really good catalyst for conversation, and the counselling skills section was definitely good strategy pointers" (participant 19)
- "I think they are fine, and don't need any more changes. I think I'd need to have some use at using the tool before I could tell you which bits I found useful and what more information I'd like in them" (participant 20).

All three Teachers of the Deaf agreed that they would use the tool as it's currently presented. Participant 20 reasoned that, "*I think it would engage kids so much more than just a discussion with me*" (participant 20). They also all thought there was a need for the tool in teacher of the Deaf sessions with hearing-impaired children, but they could also see some issue with it being used:

"Oh yeah, I think there is a need for it. My only concern would be if something came out in the session and then it wasn't followed up. You know, where the child brings up their problems, and everyone thinks that's really interesting but then there is nothing done. There also needs to be a way to share that information [with other professionals]" (participant 18)

- "Yeah definitely, I think it could be really helpful in Teacher of the Deaf sessions. In terms of issues with it being used, I think perhaps the current look of it when presenting it to older kids/teens" (participant 19)
- "Yeah I do, definitely. I think it is necessary and would be really helpful. I think my worry would be that I wouldn't be asking the right questions" (participant 20).
- All three Teachers of the Deaf thought that it wouldn't be wise for parents to have a role in the use of this tool:
- "I think the minute you start putting tools into the hands of parents to assess and analyse their children, I think a really dangerous territory to go into because they've got their own perspective on it and if there is something that is coming out where the child's not coping they can often interpret it as their own inability to work with their child or do the right thing by their child, and they might continually try to correct the child. So sometimes the parents can have their own agenda. I think having a child with a hearing loss is difficult enough as it is, so I think the parents should only observe [the professional using the tool] and then there can be a discussion with them afterwards" (participant 18)
- "I think it would probably be better for the parent to observe as a rule. I don't think it would be that helpful for parents to use on their own, as they're too emotionally invested to take a step back and see the bigger picture unfortunately" (participant 19)
- "I would say observing would be better. I would be a bit sceptical of a parent using it because the child might give an answer that the parent might want to hear, so I think you'd get a better answer with a professional use of it" (participant 20).

They all thought that the tool has the potential to enhance/improve the outcomes of paediatric rehabilitation. Participant 19 also added, *"it could definitely play a role as an option in a number of tools that are or should or could be available"* (participant 19). They all also felt that the tool would this tool be useful for obtaining both the child's perspective of their hearing loss and helping the child. They felt that needed to be more additional skills and resources available to enhance the use of this tool in the rehabilitation of hearing-impaired children:

- "If it is going to be used as a counselling tool, then definitely some counselling training and advisement to give us a greater understanding of that side of it" (participant 19)
- "Skill-wise would be question asking and through practice, training on using the tool, and flash card to [give examples on] obtain specific information [from the child]" (participant 20).

Further questions that the Teachers of the Deaf added in addition to those on the summary form that the tool could potentially be used to address included:

"How are they coping with other children outside?"

"What kind of play do they find difficult to interact in on the playground?"

"Which friends help them and how do they help them?" (participant 18)

"How does the child self-advocate?"

"How does the child go about telling others about their hearing loss?" (participant 19)

"What is the child's ability of recall memory when talking about situations?" (participant 20)

- Participant 18 elaborated that:
- "I would also like to see a set of questions you could ask the child to address these questions posed for each of professionals that the tool could potentially address. The questions in the supporting documents were okay but they could be built on with this. I really like the summary table" (participant 18).

3.5 Psychologist Interviews

Participant 21's interview was unstructured and was a more informal discussion on his thoughts on the tool, whereas participants 22 and 23 were interviewed using the interview questions as shown in Appendix F.

3.5.1 Reactions to the 'My World' tool and current methods of obtaining and evaluating information from the child's perspective

The first reactions to the 'My World' tool by the psychologists were:

- "I think there is a lot of potential in it. I thought it looked really basic, and I didn't know if it was age appropriate, although I really liked the visual-ness of it though" (participant 22)
- "When I saw it for the first time, I thought it was really useful, that it could come in handy when working in oneto-one sessions with the kids that I work with" (participant 23).

In responses to comments by audiologists to the tool from '...it's the best innovation I've seen for years in paediatric rehabilitation...' to '...without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain...', the psychologists responded:

- "I don't know in terms of how much extra time it would take if it is a conversation, and I don't think it would be that hard to learn how to use the tool. I do think that it is delving outside of their [audiologists] role a bit, as it's a skill of asking effective questions and there is a fair bit of that. I could understand if people felt uncomfortable by in because it might blur boundaries. My concern would be people who do jump in and do things when it's not their area and turn it into a [psychology] counselling tool which it shouldn't be" (participant 22)
- "I must admit when I was watching the videos I though it looked more like a counselling session, and I thought this would be something that would be more in my domain to work with kids in this way therapeutically. I wasn't really sure if it was the role of the audiologist as well. It may as well be, but is very much issue like how children are feeling and social-emotional learning and this didn't strike me as something that audiologists would naturally do" (participant 23).

Thus the psychologists voiced strong opinions on job role boundaries and the use of traditional counselling methods.

In terms of their current methods of obtaining information form the child's perspective of their hearing loss in a paediatric session and evaluating how a child is managing to go about his or her daily life with hearing loss at home, at school and in social situations, there were two differing views and methods on this from:

- "Classroom observation of the child to watch for behaviour concern, talking and obtaining information from the parents. My role is mainly [psychological] testing of children rather than counselling per se as I see the children up to Year 4, such as cognitive assessments, and it is not specific to the hearing loss" (participant 22) to
- "I might obtain that information talking to the child using visual prompts such as using drawing, and I don't look at it mainly from a hearing loss perspective though, but I would not just talk to them, there needs to be visual prompting. I also talk to the Teacher of the Deaf, their mainstream teacher and parents also to obtain this information" (participant 23).

In terms of evaluation, again there were differing views:

- "There are a range checklists, but these are more so on developmental histories, a parent report sheet, a class teacher report sheet and a visiting teacher report sheet. For kids that are older there are self-questionnaires on what they see are their strengths, their difficulties – the strengths and difficulties questionnaire (SDQ). There may also be an informal discussion with the child, and this is more so for older children. The local school psychologist will actually do the counselling role for the child mainly, although I think it would be really important if the child saw a psychologist for counselling who had a greater knowledge of dealing with hearingimpaired children" (participant 22), and
- "No evaluation process, just an informal session talking with the child. I don't use any questionnaires, as I feel my role is more of a counselling one. There are some tests I do to assess developmental stages, such as educational, academic or cognitive tests, but I feel that counselling should be the main focus and developing the child's social-emotional learning" (participant 23).

3.5.2 Reactions to the 'My World' tool videos

One psychologist found the instructional video helpful and the other did not:

- "I don't think it was very helpful, I preferred the demonstrations of the tool being used. It was a bit too simple" (participant 22)
- "I found it very helpful, as it showed what was in the kit and a little bit on how to use it. To see how to really practically use it, the later videos were much more informative for me" (participant 23).

There was also differing views on the Kathleen and her family video, and whether they thought it was relevant and if it highlighted a need for the tool.

- "I thought it was interesting. I thought it was relevant but I don't know whether it exactly highlighted a need for the tool. It did highlight how important early intervention is though" (participant 22)
- "I thought it was really informative and it gave a really good perspective of the needs of young adults. I thought it would also be a really good video to show our [hearing-impaired] Youth Leadership team. It was really heartfelt and honest. I think it showed a lot of the struggles of hearing-impaired kids and I think a lot of them would relate tho this. It absolutely did highlight a need for the tool, and the need to discuss socialemotional things around hearing loss. It was a very powerful video" (participant 23).

In response to the videos of the tool in use with an audiologist and a child, questioning skills and having a version of a psychologist using the tool were the main comments raised.

- "Depending on the audiologists, the better they were at asking the questions skilfully, the better it was. It was really interesting to see the parental feedback in one of them. I found them really good, helpful and insightful. I wonder if we would [get different information out of the child] if there was an example of a psychologist using the tool – I think it depends on the level of experience, but I would really need to see this first. It would be interesting to see a version of a psychologist using it as more of a [psychology] counselling tool" (participant 22)
- "I found them very informative and it was really good to get a concrete understanding or example of how they were shown and how it worked with really diverse kids as well, and how it worked for each one of those children. They really showed the flexibility of the tool also and how it could be used in such a multi-faceted way. I think it would have been good to see examples where the child did not engage so much with it and it would be helpful to see if those children were drawn out by using the tool. I think it would have been really interesting if I could see some examples of a psychologist using the tool and how it would be different or similar to audiologists using it" (participant 23).

The psychologists' felt that there were two main things that should be addressed with audiologists using the tool and to make it more intuitive. These included:

- "I don't think it's training on the tool needed but actually an understanding of using skilful and effective questions because sometimes you can put words into a child's mouth with the type of question you ask. You need to make sure you're not biasing any answers by putting words into their mouth or putting them in a corner. There is a real skill between open and closed questions and it's not easy to ask effective questions" (participant 22), and
- "I think there definitely needs to be some basic psychology training skills given to audiologists if they were to use this tool really successfully" (participant 23).

They both agreed that the tool allowed the audiologists to obtain meaningful information about the child's perspective of their hearing loss.

- "Yeah definitely, as there are things that might have been missed if they had not asked the child with such a visual prompt or the parents might have given you assumptions on their child's perspective" (participant 22)
- "Absolutely. I think it was very child- centred, very child-friendly, and very user-friendly as we know that our kids struggle sometimes orally and it was very hands on. I think its use definitely draws more out of the child, and it looks fun, rather than just sitting down and talking" (participant 23). Participant 23 also added in comment on the videos that "I loved the idea that they explored a lot of the social relationships. It was really empowering for the child, and that is what we want to aim to do anyway. It's also really great for rapport building with the child because it is really non-threatening" (participant 23).

3.5.3 Paediatric rehabilitation and counselling skills

Both psychologists agreed that audiologists, psychologist and Teachers of the Deaf all have a role to play in the counselling of hearing-impaired children, but that the scope of counselling should vary.

"Counselling can be a real skill, and you need to have great skills in asking effective questions, so if we are talking about traditional counselling then definitely the psychologist. With general questioning, I think audiologists and Teachers of the Deaf have a part to play also. I think Teachers of the Deaf might have a stronger part to play as they would have a stronger rapport with the child" (participant 22) "I think some initial and preliminary counselling skills for those two roles are really, really important. If it comes about that the issues are more of an emotional nature and need to be addressed more in depth manner, I think that's really important to involve other people such as psychologists and social workers. So I think there needs to a role played by everyone as a team because feelings and social-emotional learning is so much part of everything about the child anyway, so it's hard to separate it really" (participant 23).

Participants 21, 22 and 23 also felt that the use of family-centred care and patient-centred care were compatible.

- "I don't think it's either or I think you can be family-centred and child-centred at the same time. Even with a three year old, you should still be thinking about that child's individual needs and experiences" (participant 21)
- "I think it's important to have both in conjunction. Yeah I think it [bring patient-centred care in earlier], as the tool would give you an avenue to do that" (participant 22)
- "I think the two are compatible, but I don't think always the two are compatible. Certainly as the child gets developmentally older, particularly going towards the teenage years this is when the child's going to naturally separate from their parents and have their own opinions about what they want to be doing, and this is probably when we need to be focusing more on the child. I think this tool could help to bring in child-centred care earlier" (participant 23).

When questioned on their opinion as to whether some knowledge/adaptation of play and narrative techniques could help audiologists to explore issues with young hearing-impaired children using this tool or whether within the boundaries of our expertise or stepping into dangerous territory, they had quite strong opinions but did agree that knowledge of them would be helpful.

- "I think it depends on if you know your boundaries or not, and how you are going to use the tool really. If you're going to look at play therapy and you are really clear on what your goals are and they are not overstepping boundaries and it's a really experienced audiologist then yeah, I think it could be done, but if you're a person that does blur boundaries and tries to think you can get into other areas then yes it could be dangerous. I wouldn't call it narrative and play therapy for audiologists though as the terminology might scare them, as they are much psychology terms" (participant 22)
- "That's a really interesting question. I think it it's a really good tool and I think it is really important for those using the tool to have some knowledge of these skills. I guess my concern is if it is used all the time with these that there is the danger of overstepping some boundaries, where professionals aren't fully trained in those areas if there are particular issues that come up in the session, whether the audiologist would have the knowledge or the skills to discuss those issues, and whether they would be dealt with appropriately. If there was training involved in using this tool, I think that potentially audiologist could adapt these therapy techniques" (participant 23).

Both psychologists perceived a gap between the counselling by an audiologist and a psychologist and felt that this tool could be successful for bridging the gap between the roles of audiologists and psychologists:

- "I think so, but I'm not quite sure, as I'd have to see some audiologists in a counselling role first. Yeah I do think it would be [successful for bridging the gap]" (participant 22)
- "Yeah I do, because of the training and expertise for each professional, especially in addressing the socialemotional needs of the child. I think this tool is one thing that could help to try and bridge that gap" (participant 23).

They also perceived that they felt that there was a gap in helping hearing-impaired children as they may not have a good understanding of hearing loss from the child's perspective:

- "I think no, at times I wouldn't because I would get that information from the parents or teacher, and not from their perspective necessarily, so yeah this is a gap" (participant 22) and
- "I think it is a gap yes, especially with the younger kids where they find it really hard to articulate their perspective of their hearing loss, older kids find it easier, but this [tool] would be particularly useful with the younger ones to give them more a voice. There is definitely a gap! I also think we [the professionals] don't ask the questions on hearing loss from their perspective as much as we should be" (participant 23).

When questioned on whether they had extensive knowledge of Erik Erikson's stages of psychosocial development and Jean Piaget's theory of intellectual and perceptual development and how these relate to the psychosocial features of hearing-impaired children, they responded:

- "I learnt a lot of this back in my uni days. I wouldn't be able to recite every single stage now though. I do know roughly how they would relate to the psychosocial features of hearing-impaired children though, and I did think of this when I was watching the videos, so yeah you could definitely match up things there" (participant 22)
- "This takes me back to my uni days. I would probably have to refresh my memory on these and brush up on these theories, I couldn't recite them. I am not sure how these would relate to the psychosocial features of hearing-impaired children but I should, but I do think they are important to the use of the tool. Although I think you could still use the tool without knowledge of those theories though, and just as general way to gain information form kids" (participant 23).

In response to being asked if they felt there needed to be an alternative method for the counselling of hearing impaired children and if there were issues that were not addressed with current clinical methods, the psychologists responded:

- "In my role, I don't really counsel kids with hearing loss, so I don't know, but I think if you haven't been able to engage with the child and build a rapport with them then definitely you need to look at alternative methods for the counselling of hearing-impaired children. Issues I can see with it are if the professional is invested, and if the most effective method or style of therapy of using the tool has been used" (participant 22)
- "Hopefully from the psychologist's side of things I would hope that the current methods are effective, but there is always a different tool we can discover, such as this one, that can help us more. From the audiologist's side of things, yes there is probably room to improve effectiveness of counselling. There are probably things that are not addressed with current clinical methods and I feel there needs to be more specialised tools for hearing-impaired kids, such as this one. Often I'll use tools that are useful for any child with an issue and I'll use that with hearing-impaired kids but there's not very many specific tools or methods that I'm aware of that can be used with hearing-impaired kids" (participant 23).

Participant 22 and 23 also agreed that current methods could be combined with the 'My World' tool, "especially for those kids who don't learn optimally verbally and you are getting them to visually do things" (participant 22).

3.5.4 Reactions to aspects of the 'My World' tool

Both psychologists agreed that there was a use for the 'My World' tool in psychology sessions with hearing-impaired children, and thought that *"it would be really helpful to use such a visual activity"* (participant 22). They also expressed the opinion that they thought scenarios on how to use the tool to obtain certain information (such as those questions in the table in the summary) would be really useful:

- "Yeah, I think so, as I find prompting questions really helpful. I would like it more in a video format, you know for each professional. The skill of the professional can then follow on from these questions" (participant 22)
- "Yes, I'd prefer this in a written and a video format, I think both would be helpful. Maybe even having stops in the videos of the tool in use where there is a bit of an explanation by a presenter. This would be really helpful" (participant 23).

When asked whether they thought it was clear on how to use the tool as it is currently presented, both psychologists thought it was:

"In overview, yes. Although there needs to be training in the questioning skills, you can't really just go off and use it from looking at it" (participant 22)

"Yeah, I think it's fairly clear, but there is room for improvement definitely" (participant 23).

They also had ideas on whether they thought the tool needed development and what they'd like to see done differently:

- "So there's [a board] for the home, one for the school and one for the outdoors, but I think there also needs to be another social setting like a shopping centre or a better playground" (participant 22)
- "Yeah, you could potentially add in more feeling cards, as from a psychologist's perspective that would be really helpful. For example, confused, angry or frustrated, as these are the feelings that hearing-impaired

kids talk about to me quite often. I really think that you should be able to put the hearing aids on the people as it's the kid's identity – this really struck me as important. Also may things like additional aids such as a BAHA (bone-anchored hearing aid) and glasses to incorporate more of the child's identity. I think 3D objects would be easier for the kids to manipulate, as the 2D is a little bit flimsy, and 3D would be much better with those kids who aren't so good with their fine motor skills. Obviously it would be more expensive to produce in that form but I think it would be much better, as kids are mainly used to playing with 3D figurines – it is part of what they do. More written prompts along the lines of the questions that could potentially be address by using the tool in your summary would be fantastic, and also a booklet form of all the written material would be great, like an instruction manual so it's all in the one spot. I think it would be really good to have separate sections for the different professionals and to also include some of the information that is on your summary here, as it is pretty comprehensive and excellent" (participant 23).

"I think you need to actually have more narrative about the developmental stages of the child. As I was saying before if it's a three year old or a seven year old or a twelve year old or a fifteen year old you're gonna need to be able to localize using this structure. There should also be more items – it's a bit limited as obviously older adolescences are not going to engage with this particular model. There should be some capacity to customize it to the developmental status and age range of the child. I think you'd need some sort of guidelines for audiologists on how to use it, what age range, what this is going to apply to, and strategies for using it. There really also needs to be scenarios given [to professionals]. I think there needs to be a better instructional video which actually shows you how to engage the child and how to use the tool for specific outcomes" (participant 21).

In response to what age they thought was most appropriate for the 'My World' tool, and if they thought different packaging for different ages would be good, the psychologists reported:

- "6-9 years old as it is now. If it was developed more I think the age range could be explained to 3-13 years. I think it could be adapted for different age groups I think it needs to be more three-dimensional for younger kids and I think it'd be good to have a teen version" (participant 22)
- "I think it would be good to have a teenager version and have some of the figures look at bit more teenagerish. Maybe also to have a board for a shopping centre, theatre or a cinema – somewhere noise is going to be an issue, and the things they do socially. As it is now, for 6-12 years. With having different versions I think the tool could be used with 4-20 year olds" (participant 23).
- "Primary school age, up to 12 years" (participant 21).

In response to their opinions on the suggestions for use at different psychosocial stages of development and the functional skills screening tool, the psychologists felt they were very helpful.

- "I think definitely the suggestions are good, I think the information on the different developmental ages is great and you can use it as a guide. I think [the functional skills screening tool is] a great multi-disciplinary tool to be shared between professionals to fill-in" (participant 22)
- "Yeah, I think [the suggestions are] a great overview to start with. I really like the activities column; it's really practical, user-friendly and really helpful. This screening tool looks really helpful, especially for use in a multi-disciplinary team in programming, as it's a great overall view of the child" (participant 23).

The psychologists also thought that the 'My World' tool should be used by audiologists, psychologists and Teachers of the Deaf, as well as other professionals such as *"speech pathologists"* (participant 22) and *"occupational therapists"* (participant 23). They thought that the tool should be used by audiologists as:

- "Mainly a screening and referral to a psych and also counselling in relation to hearing strategies and hearing aid and equipment usage" (participant 22)
- "I think it is good for initial rapport building which I think is sometimes not done very well by audiologists, and then counselling on hearing strategies in different environments, and initial information getting for possible referral to a psychologist if there were alarm bells" (participant 23)
- "I absolutely see this tool as a referral pathway [from other professionals to psychologists] and that would probably be its key value" (participant 21).
 - The thought that the tool should be used by psychologists for:
- "social-emotional wellbeing counselling and counselling around behaviour and learning concerns and social awareness" (participant 22)

"I think psychologists should use this tool to counsel on social-emotional wellbeing, but also for rapport building and hearing strategies, but in a more in-depth manner than an audiologist, and you could also use it on a more regular basis" (participant 23).

In terms of when they thought the tool should be used by a psychologists included:

- "I think it needs to be used when there has been a referral in regard to concerns in behaviour, learning and social-emotional wellbeing. In cases where there has been a referral from an audiologists or a Teacher of the Deaf" (participant 22)
- "Initial rapport being and when there is a need or an issue has been highlighted that needs to be explored more. I would probably initially use it with a new child I would see just to see if there are any issue to start with and then bring it out again if there was a need. It's also a good tool for reinforcing when things are going well also" (participant 23).

Other uses they could see for the tool in psychology included:

- "Definitely in one-on-one sessions with kids, or maybe in a pair or a group of students to do roleplaying situations on how to communicate with others" (participant 23).
- In terms of a speech pathologist using the tool, it was though they could use it "to help with children's language and vocabulary, and talk about communication side of things" (participant 23).

When asked their opinion on the documentation form and the supporting documents, they responded:

- "I think [the documentation form] is pretty good. There needs to by psychologist listed under the section what actions have been agreed on. I think using this one as a generalised form for each of the professionals is okay" (participant 22)
- "For the supporting documents, I think the general questions for asking in regard to the environment, like the home, the school and the outdoors are really good. I'd like the supporting documents in a booklet form with the tool. I really loved your summary and I think some of this information would be fantastic to include - it was a real guide for me when I looked at this [tool] for the first time" (participant 22)
- "[The documentation form] is okay. I'd like to see it in more of a table format. I like the strategies and challenges section, and that it includes members of the professional team, although it should also include psychologist. I think that a table form would be easier to just jot things into, also would be good to see follow-ups on it also. Also an area for demographics would be good like a space to fill in the child's name, date of birth, therapist's name and date" (participant 23)
- "The listening guide is really good for jogging your memory for the different areas you could address, and is quite helpful. I like the questions for teens – there are some good intro questions, but I would like more specific examples of questions addressing the questions in the table in your summary. There is a little bit on counselling strategies here but I think it would be good to have some more on this" (participant 23).

Both psychologists agreed that they would use the tool as it is currently presented. They had differing ideas on whether parents could have a role in the use of this tool with their children, but they both agreed that parental observation would be good:

"I think it should be more observation only, as parents would bring in their own biases" (participant 22)

"I think parents could use it but they would need to have a bit of training on how to use it. I think they would be good observers, as shown in the videos, and seeing their child use it to show their world" (participant 23).

They also thought that the tool could enhance/improve the outcomes of paediatric rehabilitation because "*it really makes you stop and think about getting information from the child's perspective*" (participant 22) and "*it is just so child centred*" (participant 23). They also both thought that the tool would be successful for bridging the gap between the roles of audiologists and psychologists. They commented that tool be useful for obtaining both the child's perspective of their hearing loss and helping the child, "as they go hand in hand" (participant 23), and thought that in order to make to tool more intuitive for an audiologist to use that there needed to be "practice and mentoring sessions as well as effective questioning strategies training" (participant 22) or "an actual training course, like a one day course, or something, and definitely more counselling skills taught" (participant 23).

Further questions that they supplied that they thought could potentially be addressed by using the tool in addition to those in the summary included:

"How does the child relate to other people?"

"Does the child respond appropriately behaviourally?"

"Does the child pay attention?"

(participant 22)

"Does the child experience bullying around their hearing-impairment?"

"Does the child have a group of friends that they feel comfortable with?"

"Does the child feel isolated at play time?"

"Does the child have an awareness of their strengths?"

"Does the child think that other children speak about them behind their back?"

"Does the child have a good awareness and vocabulary for their emotions?"

"Can the child problem solve around social difficulties?"

"Can the child regulate their own emotions?"

(participant 23).

3.6 Hearing-impaired child interviews

After building a rapport with the child, difficulties hearing at school were discussed. Participant 24 reported:

"Sometimes when the children start to chat and it gets noisier and noisier, but my teacher and I have a special symbol to tell them to be quiet. When I do this, the teacher tells everyone to quieten down" (participant 24). The special symbol that she showed was a hand wave circle around the ear a few times. Participant 25 reported that "Sometime I have trouble hearing in the classroom, especially when the battery runs out". When this happens she reported "Well I just put my hand up and say I need to change my hearing aid battery. My teacher will go and get the batteries and I will change it" (participant 25). Participant 25 reported that she likes to sit at the back of the classroom but "only because I have my FM system". Therefore, both 8 year olds felt comfortable telling the teacher when they have trouble hearing. Both children reported that they use their FM systems for most of the day at school, and that school was the only time they used it. Participant 25 highlighted her issue with the use of the FM:

"What about when you are using the FM and one of the other students in the class asks a question, can you hear them?" (Researcher)

"Um, well sometimes I can but not really" (participant 25)

"Does your teacher repeat what the student has said to you?" (Researcher)

"Yeah sometimes she does" (participant 25)

"Does she remember to do this?" (Researcher)

"No only when I put my hand up and say I didn't hear that" (participant 25)

"Do you do that much?" (Researcher)

"Yeah" (participant 25)

"Are there times where you don't put up your hand to get the teacher to repeat what the student has said?" (Researcher)

"Well sometimes I get to the stage where I can't be bothered putting up my hand" (participant 25)

"And why is that?" (Researcher)

"Because it's just annoying and something I have to keep doing" (participant 25)

"Have you tried asking the teacher to do this all the time so you don't have to keep putting up your hand?" (Researcher)

"Well I have asked her a few times but she doesn't remember that" (participant 25).

Participant 24 also reported an issue with using her FM system:

"Sometimes it makes different noises like zzzsshhhh. I don't know what it is though" (participant 24)

"What happens when the zzzsshh happens? What do you do?" (Researcher)

"I tell the teacher, and she'll check it, but I'll usually just miss hearing stuff if she doesn't know how to fix it" (participant 24)

"How do you feel when you can't hear properly through it for the rest of the day?" (Researcher) *"Unhappy really"* (participant 24)

These comments highlighted that they were trying to self-advocate when they can't hear, but that it affects them emotionally when they can't hear properly, and that they may not be fully aware of the limitations of their assistive devices. Participant 25 reported that she doesn't use the FM system for

sport class and that she finds it frustrating when she can't hear, however participant 25 feels happy to move seats in class when she can't hear so well.

Participants 24 and 25 both reported that their Teacher of the Deaf doesn't help them with ideas of what to do in difficult listening situations:

"So your visiting teacher, does she help you in situations where you can't hear or tell you what you could do to hear better at school in some situations?" (Researcher)

"Um no" (participant 24)

"So what does she help you with?" (Researcher)

"She has a discussion with me" (participant 24)

"What do you talk about?" (Researcher)

"The weekend, holidays.... She comes three days a week" (participant 24)

"Does she check your hearing aid or have a look at your cochlear implant?" (Researcher)

"Sometimes to make sure it's working okay" (participant 24)

"Does she help you with some of the work that you do in class?" (Researcher)

"Yeah, she helps me with some classwork" (participant 24)

"What does she help you with?" (Researcher)

"She helps me with maths" (participant 24)

"Does your visiting teacher help you by giving you some ideas of what you could do in places where you have difficulty hearing?" (Researcher)

"No, but she does help me with the maths that my teacher doesn't really help me with – she helps me mostly with my classwork" (participant 25)

"Would you like it if she help you come up with ideas of what you could do to help you hear better in the classroom or playground?" (Researcher)

"Yeah I would" (participant 25).

In terms of playing in the playground, participant 25 prefers to play with "people on the playground that don't talk that much and we just play chasey" because it is "easier" and "I don't need to do anything [if I can't hear]". Participant 24 responded that "everybody is on the playground and it gets so noisy" so she gets "[her friends] to find a quiet place".

They only reported difficulties at a park playground when other kids were far away, and they tended to go over to the children when they can't hear. Strategies were not expressed to be used much at shopping centres, and they reported they made sure they faced their family members when on public transport. Participant 25, when out at a restaurant, has trouble hearing and usually asks people to repeat themselves to her, however her self-advocacy and self-efficacy drops if she can't understand them after a few repeats:

"What happens when you can't hear others so well at a restaurant?" (Researcher)

"Um, get them to repeat what they are saying" (participant 25)

"What if they've repeated it a few times and you still haven't understood what they've said? What do you do then?" (Researcher)

"I say it doesn't matter and I didn't want to know anyway" (participant 25)

"How does that make you feel?" (Researcher)

"Sad because I've missed the conversation" (participant 25).

Both 8 year olds reported that when they were meeting some new kids for the first time and they're on the playground, that only sometimes would they tell the other children that they can't hear so well, and that it's only sometimes as they might not be included in games otherwise. Participant 24 said that with new people she sometimes won't ask them to repeat themselves because she feels shy and embarrassed. Participant 25 also said she felt left out of conversations sometimes.

At home, participant 24 readily used strategies including using the subtitles for TV, moving to another room with a family member when she can't hear, reducing background noise such as closing doors and windows. Participant 25 also readily used strategies, including having her siblings alert her when she is called by her parent from another room, using subtitles for the TV, using the telecoil on

her hearing aids for the phone, and moving to quieter areas of the house with her siblings when she can't hear.

Both 8 year olds reported that when they go to the audiologist that they really don't get help from them to come up with ideas of what to do in situations they can't hear so well in. Participant 25 responded that she does get asked where she can't hear so well and where she can hear well, though. Participant 24 said her audiologist had only told her to tell her mother and father, or to get people to repeat themselves when she can't hear. When asked what they would like the audiologist to help them with they responded:

"To know what to do when it's noisy in the classroom, and the playground" (participant 24)

"To come up with ideas on what I could do to hear better" (participant 25).

The two 8 year olds also had comments on the 'My World' tool: When asked: 'Would you prefer to be able to show me where you can't hear as well in the classroom, or at home, rather than talking to me as we have just done?', Participant 24 said "I'd prefer to show you – it's easier than having to imagine it in my head" and participant 25 said "I think it a really good idea! Yeah I would do better to show you". They spoke about how they'd like the hearing aids to be able to be put on the people, and they'd like other items such as grandparent figures, musical instruments, an iPad, an FM system that looks like theirs, a confused face card and noisy household objects such as vacuum cleaners, a kettle or a lawnmower.

Participant 24's mother also voiced her opinion on the 'My World' tool, responding that

"I think it's such a great idea, firstly because it looks fun and like some sort of game that children could have a good time using. I think you would get more out of children by using something like this. Sometimes children find it hard to say how they're feeling, so you know placing pictures in certain areas of the room or whatever would probably be easier for the child to explain and describe how they are feeling and where they find it difficult to hear", "I think it would really great to observe an audiologist using this tool first to get some ideas of things to ask, and I'd love to use something like this at home definitely, I think it would really bring out things around the home [where my child can't hear so well] that I have never realised", "I think it would be great to have the classroom board expanded to have a playground next to it rather than using the one on the outdoor board, as this is another area where I know my child struggles to hear her friends" and "I think a 3D version would be great if you could do it as it just makes it a bit more lifelike and real".

3.7 Hearing-impaired teenager interviews

The first reactions to the 'My World' tool by participant 27 and 27 included:

- "I think it would be really good for little kids to understand about how their hearing loss is working in that environment, and help them to think more about it. I think it's good as most kids that age find it hard to find the words to describe about how they cope in that situation, so I think that it's really good, the visual aspect of it" (participant 26)
- "Before I'd seen the videos I couldn't see how it would be useful at first, but now I think it's pretty effective, and I think it's a good idea to be honest and what it tries to do to help others" (participant 27). In response to the Kathleen and her family video the teenagers responded:
- "I think the tool would have been useful for her as a child because she explained that she missed out on a lot and only really realised it later, and so I think this showed a need for the tool, as most kids can't handle
- and only really realised it later, and so I think this showed a need for the tool, as most kids can't handle talking about it out loud so I think it would help so much – using the visual side would be perceived much better by a kid. I found listening to her reflections really interesting" (participant 26)
- "Just hearing her experiences and concerns and her fears just confirms that a lot of people feel that way and I think the tool would be good to express that out as a child. So yes it was very relevant and it did highlight a need, and I think that it's a great video to show audiologists. I could really relate to the video" (participant 27).

The following responses detail the teenagers' reaction the videos of the tool in use:

"I thought it was really good that the audiologist was offering scenarios, and this is really good for the kids to understand what they can do to help themselves. It was good having the audiologist give it direction. I really liked them coming up with strategies [to help the child]. I think in terms of having the parents there that it could be a bit pressurising because you want to make sure you're [the child] saying the right thing for them and yourself. So sometimes it's good so they know what is going on [in their child's life] but sometimes you [the child] just want to say what you think rather than having to think about what's right for your parent s to hear you say. Although I think sometimes it's good to have the parents there, as some kids like having their parents in there" (participant 26)

"I thought it was a good and that it was used well in the different situations and you could see how the different kids responded to it and how there are different things you [the audiologist] could offer as a change [to address the difficult listening situations]" (participant 27).

The teenagers had strong reactions when asked whether they thought the tool helped the child to express their perspective of their hearing loss and for the audiologist to obtain information on this:

- "Yes definitely [to help the child express their perspective of their hearing loss]. Yeah I think the [audiologists] did, I think that the kids actually talked about it more [that they might have] and say what they think" (participant 26)
- "Yes definitely helped for both, especially to help the kid to think of other options they could try in the situations [the find difficult]" (participant 27).

Both teenagers agreed that the tool needed more development. Their thoughts on what they'd like to see included/changed with the 'My World' tool, included:

- "Yeah I think that there needs to be just a few changes I think it would be good if you were able to put the hearing aids on the Figure, because it's a bit weird having the hearing aids on the table next to you because that doesn't happen [in reality] – I think that would make it so much better. I do think it is pretty good how it is though at the moment. I think there needs to be babies and grandparent [figures], and maybe another darker skinned parent Figure also. Maybe 3D would be better but that might be a bit challenging? I don't mind it how it is 2D though. I think it would good to have the tool different for different age groups, especially for older kids" (participant 26)
- "Yes, I think there could be more items, such as for the people there should also be babies and grandparents. There could also use more expressions, such as unsure, but not too many... Possibly a different environment board, such as a shopping centre. I think they [the child] should be able to put the hearing aids on the figures" (participant 27)

Both teenagers also thought that the packaging needed to be packaged for different age groups also and they particularly were interested in their being a teenage version of the 'My World' tool.

"Yes definitely, I'd like to see colours different for a teenage version, like duller colours. I think the cartoon figures are okay; definitely need more teenage object like more electronics, for example an iPad. Some personalisation would be good too, like photos, and posters – of things [the child or teenager] likes. Definitely needs more emotions objects, such as worried and confused. In terms of the boards, for the home there probably needs to be more rooms to make it a bit more realistic – just another blank room at least. I think the outdoors board is pretty good as it covers mostly everything. Maybe a beach as well as the lake? A shopping centre board would probably be really good to include also, or maybe an indoor sports centre, and different kinds of sport objects" (participant 26)

"For a teen version, I'd like to see more objects and everyday items such as more technology or more people, and there should be another environment, such as work, public transport and a shopping centre. For younger kids, maybe having 3D people would be good, as younger kids like more physical toys" (participant 27)

As the tool is currently presented, participant 26 thought that the tool would be good for 5-8 year olds, and participant 27 thought it would be good for 5-10 year olds. They both though that the tool could be used as it is currently presented. Both teens agreed that if there was another version for teenagers then the tool could be used for up to 13-16 year olds. Both teenagers also agreed that the tool should be used by audiologists, psychologists and Teachers of the Deaf. Participant 26 also noted *"My mum works with occupational therapists and so I think it would also be good for kids who have problems with motor planning. Possibly speech therapists could also use this [tool] maybe"*. They both agreed that the tool should be used primarily for helping the child with hearing strategies, and they commented that the 'My World' tool "should be a regular thing, maybe every six months maybe by audiologists, but more frequently by a Teacher of the Deaf" (participant 27) and "Probably once a month or a couple of times a term would be best. I think this would work best for a Teacher of the Deaf. I think the audiologist could use it once every year or every second year, but it depends on how

well the audiologist went into enough depth with it, and how much training they've had" (participant 26).

Both of them agreed that there was definitely a need for the tool, and when asked whether they thought that the 'My World' tool would have helped them when they were young to express their perspective to their audiologists and Teachers of the Deaf they responded:

- "Yes I do, definitely, I really wish there had been something like this when I was younger to help me. When I was young they would talk to my mum and didn't really talk to be, and the audiologist would use all fancy language, and mum would reply, but I didn't really talk about it myself. They didn't really talk to me about things in depth, it was just more "how are you going at school?" and "how are your friends?" and "are you doing any outside of school activities?", and not [asking] are you having any problems with this or that. I think it would help if things were gone though in more depth" (participant 26)
- "I think it would have yeah, as only one Teacher of the Deaf that I had when I was younger had some perspective as she would talk to me about some of these things" (participant 27).

In response to whether their audiologist and Teacher of the Deaf had a good understanding of their hearing loss from their perspective the teens said:

- "I think so, because they were well trained, but I had a different audiologist each time, and I would have liked it to have been more consistent so that they understand YOU more, because when I would see a different audiologist each time I would have to re-explain everything again and again and again. Obviously they did have a good understanding of my hearing loss, but not how I coped with it myself and how I responded to certain situations. Having the same audiologist I think would help so much with that. I think that that the audiologists need to have a better understanding than they do currently, and I feel that this tool could help with this" (participant 26)
- "I think they had a general understanding, but I don't think they really knew what I was going through though because they didn't wear hearing aids and so in theory they didn't understand from the emotion side of things" (participant 27).

Issues that were not addressed in audiology and/or teacher of the Deaf sessions currently that then teenagers highlighted included:

"They don't really talk about you personally, they just give you the details of your hearing loss now and adjust hearing aids, and they don't give strategies on how to cope at school and social stuff. The Teachers of the Deaf also don't give enough strategies to you for different situations. This is what is not addressed. When they [the audiologist] tells me that my hearing loss has gone down I feel really bad like I've done something wrong and the language they use is sometimes really adult-like" (participant 26)

"I think they need to address more emotional sides of things and self-advocacy things" (participant 27).

The older teen offered a way on what professionals could potentially do to improve helping young children to help themselves self-advocate in difficult communication environments such as:

"Having a mentoring system with older hearing-impaired teenagers to help the child [to self-advocate]. I am part of the hearing-impaired youth group here [at non-for-profit educational institution] and I think this is needed for ALL hearing-impaired kids. I feel quite safe here and people understand me and I understand them" (participant 27).

Both teens discussed that they were not very confident in self-advocating, with participant 26 saying: "I don't like asking people for things, for example ordering things, and I make someone else do it for me, as I'm worried I won't hear them call my order. Also when I go to the shops to get the paper – I avoid doing this. I feel awkward asking people to repeat themselves. I find this frustrates me when I miss what people say, and I hate pretending that I understand what people say sometimes" and participant 27 says she is "very shy and self-conscious at school". The lack of confidence in self-advocacy is evident, particularly in social environments in their answers to the questions to their own experience with school, social and home life as a child, as shown in Tables 5, 6 and 7 for participant 26, and Tables 8, 9 and 10 for participant 27.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD DURING SOCIAL ACTIVITIES					
I felt left out as a child					
I felt okay explaining to others that I am deaf or hard- of-hearing					
My self-esteem was excellent as a child				\checkmark	
I found self-advocating for inclusiveness difficult		WAN		V	
I was adequately prepared for communication strategies in social situations					
I tended to not discuss my hearing loss or difficulties with other children					
I felt able to self-advocate in social situations					
I used communication strategies in social situations to help me					
I had a full understanding of the benefits and limitations of amplification in social situations				\checkmark	
I felt okay asking for what I wanted at public places c.g. shop assistants, etc.					
I felt embarrassed asking people to repeat themselves					
As a hearing-impaired child it was easy for me to start talking to people I didn't know					
I felt I missed out on activities and things I wanted to do					

Table 5. Participant 26's own experience as a child during social activities.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD AT SCHOOL					
I was prepared for discussing hearing issues/difficulties with my teachers			1.1	preserve and	
I was prepared for discussing my hearing issues with my peers				\checkmark	
I felt able to self-advocate (for example: asking for help when you can't hear and use of FM) at school				·/	
I readily self-advocated in class			V		
I readily self-advocated in the playground				V	
I needed strategies for how to cope in the classroom					
My Visiting Teacher of the Deaf/Teacher of the Deaf adequately helped me when I had difficulties in school					\checkmark
I was not confident and was a shy child in class	\checkmark				
I used communication strategies at school to help me					
I knew how to adequately discuss things such as notetakers, education assistants and FMs to other students and teachers					\checkmark
I had a full understanding of the benefits and limitations of hearing aids at school					
I felt peers were willing to help me when I needed assistance					
I felt accepted by students at my school					

Table 6. Participant 26's own experience as a child at school.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD AT HOME					v
I adequately discussed my hearing difficulties with my parents					
I adequately discussed my hearing difficulties with my siblings					
I was encouraged by my family to self-advocate					
I felt able to self-advocate at home					
I used communication strategies at home to help me		int	V		
I had a full understanding of the benefits and limitations of amplification around the home				\checkmark	
I felt included in the things my family did together as a child	1				\checkmark
I felt left out of family conversations					

Table 7. Participant 26's own experience as a child at home.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD DURING SOCIAL ACTIVITIES					
I felt left out as a child				v	
I felt okay explaining to others that I am deaf or hard- of-hearing		~			
My self-esteem was excellent as a child	V				
I found self-advocating for inclusiveness difficult				V	
I was adequately prepared for communication strategies in social situations		v			
I tended to not discuss my hearing loss or difficulties with other children					1
I felt able to self-advocate in social situations			\checkmark		
I used communication strategies in social situations to help me			\checkmark		
I had a full understanding of the benefits and limitations of amplification in social situations					✓
I felt okay asking for what I wanted at public places e.g. shop assistants, etc.	V				
I felt embarrassed asking people to repeat themselves					
As a hearing-impaired child it was easy for me to start talking to people I didn't know				\checkmark	
I felt I missed out on activities and things I wanted to do					

Table 8. Participant 27's own experience as a child during social activities.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD AT HOME					
I adequately discussed my hearing difficulties with my parents					\checkmark
I adequately discussed my hearing difficulties with my siblings No sittings	v [']				
I was encouraged by my family to self-advocate					\checkmark
I felt able to self-advocate at home					V
I used communication strategies at home to help me				× ¹	
I had a full understanding of the benefits and limitations of amplification around the home					\checkmark
I felt included in the things my family did together as a child					V
I felt left out of family conversations		\checkmark			

Table 9. Participant 27's own experience as a child at home.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD AT SCHOOL					
I was prepared for discussing hearing issues/difficulties with my teachers			V		
I was prepared for discussing my hearing issues with my peers		1			
I felt able to self-advocate (for example: asking for help when you can't hear and use of FM) at school		v			
I readily self-advocated in class	v				
I readily self-advocated in the playground		V			
I needed strategies for how to cope in the classroom			∼		
My Visiting Teacher of the Deaf/Teacher of the Deaf adequately helped me when I had difficulties in school				v	
I was not confident and was a shy child in class					
I used communication strategies at school to help me					
I knew how to adequately discuss things such as notetakers, education assistants and FMs to other students and teachers				1	
I had a full understanding of the benefits and limitations of bearing aids at school					V
I felt peers were willing to help me when I needed assistance			ν.		
I felt accepted by students at my school			V		

Table 10. Participant 27's own experience as a child at school.

Participant 26's mother also voiced her opinion on the 'My World' tool, responding that

"I thought it might be a bit simplified if we think this tool will be the one to completely help [the child] to take charge of their communications needs, because I think the child needs to learn to communicate continually through their life, and that might come from services being able to up-skill parental communication with their child. I think parental skills are dying and especially with this 'digital' era we are coming into, I am worried that (as I work in the healthcare industry) that these children are not necessarily going to get the best speech and language development and that they are not going to overhear necessarily how people around them communicate and thus how to communicate with one another. The actual tool is going to be very helpful but I think services need to think about this aspect also. I think for a child to communicate about their life and their communication we have to make sure that the parents feel okay with the impairment, as the kids pick up on how we feel and so this impacts on how they feel and act, and I don't think services provide this to parents – I know that I haven't ever had services surrounding this offered to me. I think the tool is fantastic for having the parent watch and model question asking, as this would be upskilling the parent. I think it will be extremely valuable for the child to express how they operate in their environment. I also think that the tool would be really helpful in respect to incidental learning".

3.8 Hearing-impaired 20-26 year old questionnaire

3.8.1 Reactions to the 'My World' tool and the videos

Participant 28's first reaction to the 'My World' tool was "It could be helpful to the right target audience" and he thought it would be a useful tool to be used in audiology appointments or by other professionals "in special needs cases.... However, given standard consultations are 45-60 mins there may not be sufficient time to utilize the tool".

Table 11 shows his opinions on the videos, whereby he felt that there needed to be a more informative instructional video for audiologists. He also thought that the Kathleen and her family video was very relevant, that it highlighted a need for the tool, and that he could relate to it. He felt that the videos highlighted that tool can be effectively used to give hearing-impaired children communication strategies for difficult listening situations, and that the videos highlighted the tool's ability for the child to externalise their hearing loss.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The instructional video was informative			\boxtimes		
The instructional video needs to be more informative for the Audiologist (i.e. give detailed scenarios for the kit's use)					
The "Kathleen and her family" video was very relevant and highlights the need for the My World kit					
I could relate to aspects of the "Kathleen and her family" video				\boxtimes	
Use of the kit allowed the Audiologist to gain meaningful information about the child's perspective of their hearing loss					
Engagement of the child took some time before useful information was elicited				\boxtimes	
The videos (tool in use) highlight that the kit helps the child's communication skills, self- advocacy, and self-efficacy					
The videos (tool in use) highlight that the kit can effectively be used to give the hearing- impaired child's communication strategies in difficult listening situations					
The videos (tool in use) highlight that the kit can be effectively used for all three environmental boards (i.e. home, school and outdoors)					
The videos highlighted limitations in the design of the boards/moveable objects		\boxtimes			
The videos highlighted the kit's great ability for the child to externalize their hearing loss				\boxtimes	

Table 11. Participant 28's reactions to the 'My World' videos.

3.8.2 Own experiences with and perspectives of paediatric rehabilitation

Participant 28 agreed that there is a gap in audiologists' knowledge of the hearing loss from the child's perspective, and Table 12 shows participant 28's responses on his own experiences with and perspectives of paediatric rehabilitation. He disagreed that the current counselling methods were adequate and agreed that there needed to be alternative methods. He felt that he was not given adequate strategies on how to explain his hearing loss to others or given adequate conversational repair strategies by his audiologist when he was a child. Importantly, he felt there is a gap between the counselling by an audiologist and a psychologist, and that communication challenges were not adequately addressed by his audiologist as a child. He felt that audiologists, psychologists and Teachers of the Deaf should all address the counselling needs of hearing-impaired children. Therefore, he felt that there was a major gap in adequately addressing the hearing-impaired child's counselling needs in paediatric rehabilitation.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My Audiologist/s when I was a child had a good understanding of my hearing loss					
There is a gap in Audiologists' knowledge of the hearing loss from the child's perspective				\boxtimes	
Current methods in counselling of hearing-impaired children are adequate					
There needs to be an alternative method for the counselling of hearing- impaired children				\boxtimes	
I was given adequate strategies on how to explain my hearing loss to others by my Audiologist/s when I was a child					
I was given every-day conversational repair strategies as a child		\boxtimes			
My hearing loss was adequately explained to me (and directly explained to me) by my Audiologist/s when I was a child					
I was given adequate strategies on how to deal with difficult listening situations by my Audiologist/s when I was a child					
I was given adequate self-advocacy strategies by my Audiologist/s when I was a child and I felt I was able to self-advocate					
I was adequately prepared to manage my hearing loss at home as a child					
I was adequately prepared to manage my hearing loss in school as a child					
I was adequately prepared to manage my hearing loss in social situations as a child					
My communication challenges were adequately addressed by my Audiologist/s as a child					
There is a gap between the counselling of hearing-impaired children by Paediatric Audiologists and Paediatric Psychologists					
Counselling of the child is within the boundary of audiology expertise in rehabilitation (i.e. not just amplification and audiological test based)				\boxtimes	
	Audiologist	Psychologist	Teacher of the Deaf	All three	Other (please specify)
Who should address the counselling needs of hearing-impaired children?					
	1	1 1 114 7			

Table 12. Participant 28' own experiences and perspectives of paediatric rehabilitation.

3.8.3 Own experiences with school, social and home life as a child

Participant 28's own experiences with school, social and home life as a child, as shown in Table 13 showed that he disagreed that he received adequate strategies on how to explain his hearing loss to others or received adequate self-advocacy strategies when he was a child. He agreed he did not feel he was able to self-advocate at school and he felt that back then he did not have a full understanding of the benefits and limitations of his amplification. He also reported he tended to not discuss his hearing loss or difficulties with other children or his family as a child, and he felt that he missed out on

activities and things that he wanted to do. These responses indicate that, as a child, participant 28 had poor self-efficacy, self-esteem and self-advocacy.

S.S. C1111 D. AT SCHOOL (freezour Primery School age) Iwas adequately prepared for discussing hearing issues with my pers Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground Image: Content is the self-advected in the play ground in the self-advected in the play ground in the self-advected in the self-advected in the self-advected in the play ground in the self-advected in the self-advected in the self-advected in the play ground in the self-advected in the play ground in the self-advected in the play ground in the play ground in the play ground in the self-advected in the play ground in the play ground in the play gro	poor sen-emeacy, sen-esteem and sen-advocacy.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
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I felt embarrassed asking people to repeat themselves	I felt okay asking for what I wanted at public places e.g. shop assistants, etc.				\boxtimes	
	I felt embarrassed asking people to repeat themselves				\boxtimes	
As a hearing-impaired child it was easy for me to start talking to people I didn't know						
I felt I missed out on activities and things I wanted to do	I felt I missed out on activities and things I wanted to do				\boxtimes	

Table 13. Participant 28's own experiences with school, social and home life as a child.

3.8.4 Reactions to aspects of the 'My World' tool

Participant 28 thought that the most appropriate age group for the 'My World' tool were 6-9 year olds, and that it should be used for counselling on hearing strategies, social-emotional counselling, and as a screening and referral tool (e.g. to a psychologist). He thought that the tool should be used at annual reviews, hearing aid reviews, cochlear implantation and other candidature assessments as well as periodic educational assessments, and that it should be used by audiologists, Teachers of the Deaf and psychologists. Participant 28 also responded an opinion on whether parents should use it, reporting: "No I think it's important to maintain an objective viewpoint for therapeutic purposes".

He does not agree that the 'My World' tool can be effectively used clinically as it is currently presented, responding that *"it needs more development in assessing the responses from children"*. He also felt that in terms of skills to enhance the use of the tool that professionals need to *"[have] a focus on interpreting non-verbal communication cues"*. He felt that the needs of hearing-impaired children from professionals are *"gaining skills that would help them engage especially when they are unable to interact with a group discussion or activity"*. Other potential questions participant 28 suggested that could be addressed by using the tool, include *"Is there a need for further services? (e.g. speech pathology) and Does the child exhibit behaviour or emotional problems?*.

Table 14 shows participant 28's opinions on further aspects of the 'My World' tool, whereby he felt that the tool items were not adequate, the tool needed more development, and that the packaging should be different for different age groups. He agreed that there was a need for the tool and that it would be useful in giving the child strategies and developing their self-efficacy/self-advocacy. He felt that this tool would have helped him as a child.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The kit items are adequate in number and form		\boxtimes			
The packaging of the kit should be different for different age groups (i.e. customisation and item units)				\boxtimes	
The kit needs more development overall				\boxtimes	
A multi-disciplinary approach to the use of this kit would be beneficial				\boxtimes	
There is a NEED for the My World kit clinically				\boxtimes	
This kit could enhance/improve the outcomes of paediatric rehabilitation				\boxtimes	
The kit could work well using photos for inspiration				\boxtimes	
Open-ended questions work well with this kit				\boxtimes	
This kit would be useful in giving the child strategies and developing their self-efficacy, self-esteem and confidence				\boxtimes	
I wish there had been a kit available such as this when I was younger				\boxtimes	
I think that a kit like this would have helped me				\boxtimes	
I think that this kit has the potential to help many hearing-impaired children				\boxtimes	
This kit would be useful in obtaining BOTH the child's perspective of their hearing loss and helping the child successfully				\boxtimes	
The methods to record and preserve information need refining if the kit is to be used clinically				\boxtimes	
This kit will increase the effectiveness of counselling by Audiologists for hearing-impaired children				\boxtimes	
I feel that this kit would be a useful counselling tool with hearing-impaired children who have very limited language				\boxtimes	
I feel that more paediatric counselling skill resources for Audiologists are necessary				\boxtimes	

Table 14. Participant 28's opinions on various aspects of the 'My World' tool.

4. Discussion

Results from this study throw new light on the current scope of paediatric rehabilitation, and on the 'My World' tool and its aim to incorporate the child's perspective of their hearing loss in a paediatric session. Firstly, the tool was well received by the majority of the 28 participants, and the professionals were very embracing of a new method of counselling hearing-impaired children. Many of the professionals were worried about the time that it could take to use in appointments, but agreed that the child's perspective was one which needed more of a voice clinically than it is currently, and that a holistic perspective rather than focusing on audiological information was important. The hearing-impaired participants particularly liked the idea of the 'My World', tool due to its visual aspect.

In terms of the professionals' reactions to the two varied reactions to the tool, many of the professionals agreed with both statements. Particularly those who worked in the government paediatric services, where appointment time frames were limited, they could relate to the comment "...without audibility, our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain...". Many agreed with the first statement "...it's the best innovation I've seen for years in paediatric rehabilitation...", purely because they felt that the child's voice important to successful rehabilitation. Many felt that while the clinical technical side of audiology is important, they realised that there needed to be a balance between technical aspects and what really matters in the real world. This emphasises that having time to complete a session which includes addressing the concerns and hearing issues from the child's point of view is worthy, and that a holistic approach is desirable.

Not surprisingly, all professionals (from audiologists, to psychologists, to Teachers of the Deaf), reported they obtain information from the child's perspective of their hearing loss mainly through informal discussion means, including talking to the parent, sometime the child, and also examining information provided from other professionals. In terms of evaluating how well a hearing-impaired child is managing to go about his or her daily life with hearing loss at home, at school and in social situations, it is clear that the main formal means seems to be questionnaires that are completed by either the parents or teachers, with only one being mentioned that the child could complete (in relation to FM benefit). Some professionals also reported only using informal means (again, just an informal discussion). This highlighted that currently there is little being done by professionals to obtain the true child's perspective of their hearing loss and how they personally manage day to day, and it appears to be largely from the perceptions of others. There is no means routinely used that is at the child's level, such as play, to obtain this information. Thus it is clear that the initiative of the 'My World' tool has attempted to break this barrier in gaining the child's perspective in the rehabilitation process.

In the present study, the professionals mainly felt that it was clear how to use the 'My World' tool as it presented, however the videos helped many obtain this perception. There was much agreement from the professionals that the instructional video was useful on a basic level, but that there needed to be an instructional video on how and when to use the tool, and on its particular uses. There was indication that professionals need to be taught how to engage the child, especially if they were not keen initially. An overwhelming majority of the professionals felt that the 'Kathleen and her family' video was very relevant to the 'My World' tool, and that it highlighted a need for the tool. For those that felt it did not highlight a need for the tool, they said it showed at least that more counselling from professionals was needed for hearing-impaired children. The hearing-impaired teenagers and young adult expressed that they could relate to this video, and also felt that it highlighted a need for the 'My World' tool. They also felt this video portrayed the more emotional side of hearing loss to audiologists.

The majority of professionals felt that the videos of the tool in use showed a good example of the tool being used. Many professionals expressed the opinion that these videos of the tool being used showed children who were very good oral communicators, and showed model examples, and that they

would have liked to have seen further examples on how you would go about using this tool with children who are not so well spoken, or as willing to participate. Many also would have liked to have seen an example of the tool being used by a teenager, or with a child who communicated via sign language. The psychologists would have liked to see examples of a psychologist using the tool as well; particularly because they felt their use of this tool may be more in-depth. This indicates that professionals want to be able to see a more holistic view of what to do, what not to do, and how to use this tool with a large range of hearing-impaired children. It is especially important to consider some of these factors if there are to be a variety of professionals using this tool, because different professionals would use this tool at different levels with a child. If professionals were to use the 'My World' tool with a variety of children successfully, it is of importance that the professionals also know how to engage with children of different levels of communication, behaviour and psychosocial stage of development. The majority agreed that use of the tool allowed the audiologist to gain meaningful information about the child's perspective of their hearing loss. The biggest factor that came out of the discussions with the audiologists in relation to this was that they were unsure of what to do with this useful information, and how to be skilled in the question-asking with the child. This is why many suggested that there needed to be mentoring on the use of this tool, and more clear guidelines of what to do with the information, whether that be adjustments of the hearing aids, discussion of assistive listening devices, referral to other professionals, or counselling on strategies. From this insight, it can be seen that this is as an area that needs more development in the implementation and development of the 'My World' tool. Other comments on the videos by professionals included that they liked seeing the parental feedback, and the modelling of behaviours. The hearing-impaired teenagers thought that the most useful aspect of the videos of the tool in use were the facts that the audiologists gave the tool direction, and provided strategies to the children on what they could do to help themselves in their difficult listening environments. This was related to what they felt were issues that were not currently addressed in paediatric sessions.

The majority of professionals felt that there was a gap between the counselling by an audiologist and a psychologist provided to hearing-impaired children, and the majority also felt a gap in their understanding of hearing-loss from the child's perspective. This supports hypothesis 1 of this study, and appears to be due to a number of factors, such as that the professionals were not hearing-impaired themselves, that they actually did not know what the various roles of audiologists or psychologists were, in terms of the extent of counselling (i.e. unaware of professional boundaries), the training each profession received on counselling, and the lack of communication between professionals to maintain a multi-disciplinary approach. In terms of their understanding of hearing loss from the child's perspective, the main reasons were again; not being hearing-impaired themselves, having different priorities to cover in sessions compared to the child and their family, and simply that the child's perspective is something they just don't routinely seek to obtain. This reflected that the counselling provided by professionals may be sporadic, and may not cover all the areas they should be in regards to their respective professions. Indeed so, as the hearing impaired perspective of this study highlighted that this was the case. The hearing-impaired children and teenagers suggested that audiologists and Teachers of the Deaf routinely or occasionally ask children where they can and did not hear so well, but that they did not adequately provide counselling on hearing strategies, or address the more emotional side of things. The hearing-impaired young adult also agreed that he was not given adequate strategies on how to explain his hearing loss to others, nor was he given adequate conversational repair strategies by his audiologist when he was a child. This is alarming because such counselling is a part of the scaffolding that can help a hearing-impaired child to develop and build their sense of self-worth, self-esteem, self-advocacy and self-efficacy. It also improves their hearing ability and feeling of inclusion in their everyday environments. This was further highlighted by the fact that the hearing-impaired older teens still felt a lack of their self-efficacy and their ability to selfadvocate, as well as that both professionals and hearing-impaired participants felt that there needed to

be alternative methods for the counselling of hearing-impaired children as they felt that current methods were not adequate.

Many of the professionals felt that this tool would be successful for bridging the gap between psychologists and audiologists, because they felt it could serve as an intermediate bridge to the use of basic counselling by those professionals who are not trained as psychologists, thus making crossreferral easier. Those who were more sceptical about this role highlighted the need for training from a trained counsellor or psychologists on counselling techniques, and that the tool alone would not bridge this gap. Such training and knowledge was wanted in relation to this tool by many of the professionals. Overall, this study highlighted the fact that the tool alone would not be enough and that training on questioning skills, basic psychology and play and narrative therapy techniques would be vital if professionals other than psychologists were to use this tool. This study also highlighted the lack of appreciation of the social-emotional impact of hearing loss on children, basic Erikson and Piaget theory, and the psycho-social development, of hearing-impaired children. Some of the professionals had learnt about Erikson's stages of psychosocial development and Piaget's theory of intellectual and perceptual development. This occurred mainly in those professionals who had a teaching or psychology background. What was alarming was that none of the professionals knew how these theories related to the psychosocial features of hearing-impaired children. Many of the professionals expressed their desire that they would like to be taught more about these to improve their own skills and perspectives in counselling hearing-impaired children in their respective professions, and so it is recommended that these are taught in conjunction with this tool. Very few of the audiologists and Teachers of the Deaf had extra training in psychology or counselling skills, and some reported that many PD days or conferences did not teach in detail some of these things. Many of the professionals expressed their desire for more teaching and training on counselling and psychology.

All professionals felt that the role of counselling hearing-impaired children should be covered by audiologists, psychologists and Teachers of the Deaf. Overall, the audiologists felt that their role was to mainly counsel basics on hearing loss and amplification, however some thought that they should be addressing at least some of the emotional side of things. It was also discussed that it may be more of a cultural thing, where feelings associated with hearing loss and difficulties are not so openly discussed. Teachers of the Deaf felt that the counselling role fell to them much more than it should. This is interesting, particularly because they highlighted that they did not receive as much counselling training as they thought they should. They felt that there needed to be a much more multi-disciplinary approach to this than is currently the case. The psychologists felt that the other professionals needed to cover more of the emotional side of things, particularly because social-emotional learning is integrated in the child, and it is hard to separate. The hearing-impaired young adult also agreed with the fact that the counselling role by these professionals, and that it should not just fall to a psychologist. It also highlighted that addressing the emotions of the child was important from every professional angle.

A large majority of the professionals agreed that family and patient-centred care were compatible in paediatric audiology, and that there should not be a set time frame when there should be a transition from one to the other. They agreed that there needed to be balance between addressing the needs of the parents/family and the needs of the child, and that the child should be encouraged to participate as soon as possible in their own rehabilitation. Many felt that the 'My World' tool would help to bring about child inclusion and participation in paediatric rehabilitation earlier, and that this was desirable. Thus, the two would go hand-in hand, and emphasised the point that a holistic approach was necessary in providing successful rehabilitation to a hearing-impaired child.

The comments from both the professionals and the hearing-impaired participants highlighted that there is a need for the 'My World' tool, which supports hypothesis 2. The participants felt this, because there is no other concrete tool that is child-centred in their battery for obtaining information from the child's perspective of their hearing loss, the current methods of obtaining information from the child's perspective of their hearing loss, with the majority feeling that there was a gap in their understanding of hearing loss from the child's perspective. All of the professionals felt that they would be comfortable counselling hearing-impaired children using a tool such as the 'My World' tool in their rehabilitation, *as long as they received training in using it*. The hearing-impaired participants mostly felt a need for this tool, because they felt that it could help hearing-impaired children develop strategies for difficult listening strategies, and the hearing-impaired teenagers and young adults felt that this tool would have helped them when they were young. Clearly it can be argued from this research that there is a holistic need for the 'My World' tool.

The majority of professionals felt that the tool would allow them to obtain both the child's perspective of their hearing loss and actually helping the child, as well as that the tool would improve and enhance the outcomes of paediatric rehabilitation, which is supportive of hypothesis 3. This is because overall the professionals felt that the tool would allow a concrete method for the child to explore and explain their narrative, as well as helping the child through the pathway of self-advocacy at the child's level in a non-threatening manner. Thus, the overwhelming response was that the two go hand-in-hand.

This study also addressed what age range that the tool (as it is currently presented) should be used for, and overall the dominant age range identified by the participants is 5-12 year olds but potentially to late teens if the 'My World' tool was adapted for different age groups. The majority of all participants, including all of the hearing-impaired participants felt that the tool needed more development. The main suggestions included the need for more information on how and when to use the tool. This included the suggestion of having flash cards on how to obtain specific information from the child. Other potential areas for development included having more boards, or more development of the outdoors area, such as a shopping centre for teenagers, and the need for more emotion cards, such as confused, angry or frustrated (this was perceived by each professional area, as well as by the hearing-impaired participants). The most striking thing perceived was that the majority felt that the hearing aids should be able to be put on the figures, because this is such a large aspect of the child's identity. 3D figures were suggested to be much better for younger children, the majority of professionals felt that they would like a comprehensive booklet/book form, including all the information in the tool box, such as the documentation form and listening guide, supplementary resources, as well as the information provided in the researcher's summary. There was an overwhelming majority of participants who felt that the tool needed to be adapted to have different formats for different age groups. This supports reasoning that in order to effectively engage the child, there needed to be a format that targets the developmental age of the child. Some suggested that the best approach to this would be an online version, which could be printed, with extra items in addition to those already supplied. Therefore, there is scope to target this tool at a much larger age range, from 3-18 years, as suggested by the majority of the professionals who were interviewed. Participants felt that there also needed to be more items, particularly if the tool were to be adapted potentially for older/younger children. A computer or an iPad version was suggested with more versatility and mobility. The hearing-impaired teenagers and children felt that there needed to be more figures, such as babies and grandparents, more styles of FM systems and hearing aids, more noisy household objects and electronics, and definitely with the hearing aids to be able to be put on the figures. Many of the professionals also felt that the documentation form needed improvement, from having more room to write, to having a table format for monitoring change over time, adding in psychologist to the question on what actions have been agreed on, to having a section for demographics such as the child's name, date of birth, and date of session. Therefore, this study highlighted that there was quite a large scope for further future development of the 'My World' tool.

The majority of professionals felt that the tool needed to be used on a regular basis, such as in annual reviews, followed by hearing aid and educational assessment reviews. It was highlighted in this study, from the professional's perspective, that the use of this tool needed to be primarily postrehabilitation, and that it was not for cochlear implantation or other candidacy assessments. As for what circumstances, many of the audiologists suggested obtaining and monitoring COSI (client orientated scale of improvement scale of improvement) goals. The psychologists felt that the tool needed to be used by their profession for initial rapport building, and in cases where there had been a referral due to concerns in behaviour, learning and social-emotional wellbeing. The Teachers of the Deaf felt that they should only use it on a needs basis, or for blocks of targets (such as a socialemotional, an educational, an audition, or a language/speech target and their reviews). These suggestions are excellent starting points for focusing specific uses; however, further research is needed.

The majority of participants felt that knowledge of psychology counselling skills such as play and narrative therapy would be useful. There were many reasons for this, especially from the psychologists and some of the audiologists, who felt that asking the right questions with good questioning skills would lead to the most effective use of this tool. It is thus suggested that knowledge of these techniques and basic counselling skills would equip professionals working with hearingimpaired children to enhance the effectiveness of their paediatric rehabilitation.

The main problems that the professionals could see with the 'My World' tool were having the time to use the tool clinically, not being clear of what your goal was when using it, making sure the user is clear of their professional boundaries when using the tool with a child, not having clear protocols or steps to follow if the tool opened up issues that the child disclosed, such as being mistreated at home, as well as professionals being open to actually using a new tool in their selection of counselling methods. These are all important issues that need to be addressed if this tool is to be successfully integrated in the rehabilitation of hearing-impaired children, and it is suggested that some of these issues could potentially be addressed if training was available in the use of the 'My World' tool, and with further development of the tool itself.

All of the professionals thought that the tool would be a useful learning tool for parents to observe their child using, however many were worried that if this tool were to be put in the hands of parents, that they would not use it neutrally, and would bias the responses of the child with their own perspectives and emotions, due to their own agenda. Those professionals who did agree that it would be fantastic for parents to use also recommended that there should be training for the parents provided by the professionals, so they knew how to correctly use the tool. The hearing-impaired young adult's perspective of parental use was that the tool should be used as observational only, with a professional using the tool with their child. It would be interesting to obtain the perspectives of many parents on their thoughts and what they perceive of professional or themselves using this tool. From the mothers of two of the hearing-impaired participants, it seemed that the tool would be potentially embraced by parents. One of the mothers said she liked the idea, because it would bring out things that, as a parent, she may not have thought about. They could see the tool's role in the up-skilling of parents. From these small discussions with parents, it was highlighted that there was much scope for future research into the parental aspects of this tool.

In terms of the supporting documents, the main comment that stood out from the professionals was that the sample questions and the counselling information on the pitfalls to avoid were useful. Many of the professionals also had positive responses to the form included on Karen Anderson's suggestions for use at different stages of development, feeling that it was a good guideline to start with. They particularly liked the background on the stages of psychosocial development, and the characteristics of communication, but they would have liked more information on these two aspects. The majority of professionals felt that the functional skills screening tool would be useful with the 'My World' tool, and that it was a very holistic checklist, however most felt that it would only have successful implementation within multi-disciplinary environments, or mainly used by educational audiologists, rather than clinical audiologists who may not work in such a multi-disciplinary environment.

Most of the professionals felt that it was clear how the tool should be used, but the videos and supporting resources were most clear. Additional helpful skills and resources that the professionals

thought would help them enhance the use of this tool included counselling training and advisement, a greater knowledge of the social-emotional impact of hearing loss from the child's point of view, having material broken down for separate age brackets, background information on psychology skills, a mentoring process for professionals, and different formats for different professionals learning styles. Many of the professionals felt that scenarios on how to use the tool to obtain certain information would be useful (such as scenarios addressing the questions on the summary sheet). They thought this would be good in a written and/or video format.

Overall, the participants felt that the tool has the potential for a holistic usage by many professionals, including audiologists, Teachers of the Deaf, psychologists, speech therapists, occupational therapists and counsellors, in support of hypothesis 4. The suggested main uses of the 'My World' tool for the various professionals were:

- 1. Audiologists: counselling on hearing strategies and screening for referral to psychologists
- 2. Psychologists: counselling on social/emotional wellbeing and exploring relationships in depth
- 3. Teachers of the Deaf: counselling on hearing strategies and screening for referral to psychologists
- 4. Speech therapists: teaching vocabulary and building language
- 5. Occupational therapists: building strategies for environments
- 6. Counsellors: general counselling on social/emotional wellbeing

This gives a broader use for the tool by different professionals, and highlights that it has a much larger scope than just being used by audiologists. This supports hypothesis 4 that there are many clinical uses for the 'My World' tool. Unexpectedly, professionals found it very difficult to pinpoint specific uses, beyond the broad ones for their professions. A key aspect to this was most likely because the professionals (all but one) did not have hands-on experience with using the tool with a hearing-impaired child. Many felt that this could have been an experience that could have helped them to highlight further specific examples of the tool's use in their profession, and give them more insight when commenting on how the tool could be improved. Timing was a major factor as to why this was not included within this study.

There is much potential for future research with having professionals trial the tool in order to give more feedback on the processes that need improving and specific uses of the tool. On the other hand, many of the professionals responded rather positively to the inclusion of the table of the questions designed by the researcher that could be potentially addressed by this tool for various professionals (this table was designed to help the participants tease apart more defined uses for this tool), and they also added further questions to this table. The combined questions including the professionals' thoughts are shown in Table 15. They felt that this table was crucial for defining more specific uses for this tool, and that there needed to be more information provided on how to elicit the answers to these questions in a paediatric session in either a video or a written format. This table lends itself to further future research into defining specific uses stemming from the broadly defined uses stated above for each professional. There is also scope into researching the need and specific use of this tool by the other professionals mentioned, such as speech pathologists, occupational therapists and counsellors in the rehabilitation of hearing-impaired children.

The hearing-impaired children's experiences with school and social life highlighted the need for more self-advocacy building for difficult listening environments. They explained that it was sometimes easier to give up when they could not hear, and resigned themselves to missing out on what was being said when their only strategy was asking people to repeat themselves. This was similar to the findings from the teenagers, with their experiences as a child, leading to a poorer selfefficacy (feeling they are able to self-advocate) now they were teenagers. Some of the hearingimpaired participants felt that they were comfortable with self-advocating at home, and this may be due to a greater acceptance of their hearing loss by their family. It is of the researcher's opinion and through the works of Luterman (1999), that the feeling of the family members towards their child's

hearing loss, and their level of encouragement, can also greatly influence the child's ability to self-advocate.

Audiologist	Psychologist	Teacher of the Deaf
•What are the child's most difficult listening situations? Where	•Does the child have good self-esteem?	•How well does the child communicate with their peers?
are they? Home, school, etc?		-
•Who does the child have trouble communicating with/understanding?	•Does the child have a good self concept?	•What are the main situations where the child has difficulties hearing in the classroom?
•Is the child using their FM successfully in class? Is it helping them?	•Does the child have good self efficacy?	•How effective does the child find their FM system in the classroom?
•How does the child manage with their hearing loss at home?	•How does the child self perceive?	•What are the child's most difficult listening situations? Where are they? Home, school, etc?
•What are the child's communication successes and challenges?	•What are the child's attitudes towards self/others?	•How well does the child communicate with their classroom teacher/s?
•What are the child's limitations with their current amplification?	•What are the child's attitudes towards hearing impairment?	•What are the child's attitudes towards self/others?
•How does the child go about self advocacy? How do they feel about doing this?	•What are the child's attitudes towards their hearing aids/CIs, etc?	•What are the child's positive and negative experiences with having a hearing loss?
•What strategies can help the child in their communication challenges?	•Does the child receive emotional support from their family/friends?	•Does the child self advocate with about their hearing loss?
•How does the child perceive their current amplification (i.e. is it	•What are the child's behavioural issues in particular situations?	•How does the child feel others perceive them?
adequate)? •How does the child manage with their hearing loss with peers?	•What are the child's positive and negative experiences with	•Are the current classroom strategies helping the child
• How door the shild persoive their bearing loss?	having a hearing loss?What is the psychosocial developmental level of the child?	from their view? •What is the child's level of spoken English?
•How does the child perceive their hearing loss? •Find out if child is actually using the amplification, where and	•What is the child's level of self-reliance?	•Does the child have adequate access to the school
•Identify situations where is the child communicating	•Does the child have a good level of environmental	•How does the child perceive help from their educational
successfully? •Deconstructing with a child the communication strategies that	awareness? •Does the child have anxiety in specific situations?	assistant/ interpreter? •How are they coping with other children outside?"
he or she is already employing successfully •Identify communication challenges that are important to the	Does the child have an emotional disorder? (e.g.	•What kind of play do they find difficult to interact in
child	anger/frustration/impulsivity)	playground?"
•Are there strategies that the child is already employing successfully in one situation that might help in another?	•Does the child have behavioural control?	•"Which friend's help them and how do they help them?"
•Uncover any maladaptive strategies that need to be addressed?	•How does the child behave non-verbally?	•How does the child self-advocate?"
•Help the child to 're-story' his or her perspective to highlight strengths and successful strategies	How does the child relate to other people?	•How does the child go about telling others about their hearing
•Externalise the hearing loss	•Does the child respond appropriately behaviourally?	•"What is the child's ability of recall memory when talki situations?"
•Co-formulate strategic solutions to communication challenges that are practicable	•Does the child pay attention?	•Engage the child in his or her own rehabilitation program
•Explore self-efficacy issues that may hinder successful employment of communication strategies	•Does the child experience bullying around their hearing- impairment?	•Evaluation of intervention to date
•Rehearse self-advocating vocabulary to use in real-life communication situations specific to the child	•Does the child have a group of friends that they feel comfortable with?	•Externalise the hearing loss
Problem -solve new strategies for communication situations that are not working and causing unhappiness	•Does the child feel isolated at play time?	 Co-formulate strategic solutions to communication challenges that are practicable
•Engage the child in his or her own rehabilitation program	•Does the child have an awareness of their strengths?	•Explore self-efficacy issues that may hinder successful employment of communication strategies
•Evaluation of intervention to date	•Does the child think that other children speak about them behind their back?	Rehearse self-advocating vocabulary to use in real-life communication situations specific to the child
Negotiation of COSI goals to be addressed by future intervention		•Does the child have an awareness of the limitations and benefits of their amplification?
Planning of future intervention	•Can the child problem solve around social difficulties?	•Does the child understand how to use their new technology
•Does the child have self-awareness of their hearing loss?	•Can the child regulate their own emotions?	•How does the child use strategies by themselves?
• Does the child confident to talk about their hearing loss?	•Engage the child in his or her own rehabilitation program	• Flow does the child use strategies by themselves? • Is the child coping well in their natural environment?
 Due the child have an awareness of the limitations and benefits of their amplification? 	•Evaluation of intervention to date	Is there a need for further services/ intervention/support?
•Does the child understand how to use their new technology	•Externalise the hearing loss	Does the child have self-awareness of their hearing
 correctly? e.g. hearing aids/ FM systems What is the child's level of family involvement in rebabilitation? 	•Co-formulate strategic solutions to communication	Planning of future intervention
•What does the child understand about their hearing loss?	•Explore self-efficacy issues that may hinder successful	
•How does the child use strategies by themselves?	employment of communication strategies •Rehearse self-advocating vocabulary to use in real-life	<u> </u>
To the shild coming wall in their natives! anvironment?	communication situations specific to the child	
 Is the child coping well in their natural environment? Does the child need assistive listening devices in certain areas 	Planning of future intervention	
of life? •Does the child have an awareness of the limitations and benefits		
of their amplification? •Does the child have the knowledge of management of their		
hearing loss on their own in an environment? •Is there a need for further services/intervention/support?		
•Does the child exhibit behavioural or emotional problems?		

Table 15. Questions that the tool could be used to address in a paediatric session. Questions combined of those proposed by the researcher and from those suggested by the professionals.

The hearing-impaired young adult reported having low self-esteem, self-concept and selfefficacy as a child, as well as not feeling able to formulate strategies for dealing with difficult communication strategies, or fully understanding the benefits and limitations of his amplification as a child at school, at home, and during social activities. This led him to feel left out, and he felt like he missed out on activities and things that he wanted to do. Therefore, from this study, it is important to emphasise that the perspectives of the hearing-impaired subjects have suggested that there needed to be more counselling on hearing strategies by all professionals particularly in relation to self-advocacy and self-efficacy, and that there is a need for this tool for hearing-impaired children, and that communication strategies were what they felt was most needed from the service. Due to the small number of hearing-impaired participants, there is much scope for future research into the views of a much larger hearing-impaired population.

The main limitation imposed on this study was the recruiting of the hearing-impaired participants, largely due to time factors in which to complete this study, and also limitations posed by the various routes of recruitment, which resulted in a very small number of hearing-impaired children, teenagers and young adult participants.

In conclusion, this study has shown that there is a need for the 'My World' tool from both professional and hearing-impaired perspectives, and that defined uses can and need to be formally established for each professional. All four predicted hypotheses were supported. The tool has many other potential uses suggested by professionals, beyond the realm of its use with hearing-impaired children, such as for children with other chronic lifelong disabilities, or perhaps even as a counselling tool for normal children. These are all worthy of future investigation.

Most importantly, this study highlighted that counselling on hearing strategies is an area that needs to be improved for paediatric rehabilitation. In terms of future research and/or future implementation of the tool in clinical use, this study highlighted that further development of the tool is needed, and that structured mentoring and training is required with the use of this tool. Additionally, psychology counselling skills (general skills, play and narrative therapy techniques) should be adapted for use with this tool and there needs to be more study into the hearing-impaired perspective of this tool. Psychosocial development and its relation to hearing-impaired children needs to be covered more thoroughly for professionals in their university courses, and/or in relation to potentially implemented training associated with the 'My World' tool.

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APPENDIX (A) – AUDIOLOGIST QUESTIONNAIRE SUMMARY

The Need and Uses of the Ida 'My World' Counselling Tool in Paediatric Rehabilitation for Hearing-impaired Children

Jessica Round, Master of Clinical Audiology, Supervisor – Karen Parfitt & Dr Robert Patuzzi

Introduction: Because of their reduced vocabulary and communication skills, a child with a severe hearing loss can be at a great disadvantage in explaining to parents, teachers and professionals the problems they face day to day. The 'My World' tool, which is being developed at the Ida Institute, Denmark in collaboration with professionals from the US and the UK, is intended to be used during a consultation session to support a dialogue about communication situations between a professional and a young child. The tool is employing natural play, to enable a child to express actions, thoughts and concerns around communication situations in their lives, and providing the necessary physical objects to enable the child to problem solve and formulate logical solutions.

Research-based best practice in audiology is currently family-centred in paediatric rehabilitation, and patient-centred in adult rehabilitation. At what age should rehabilitation transition from one to the other? Inherent in the development of this tool is the assumption that motivational engagement is as critical to successful paediatric rehabilitation as it is to successful adult rehabilitation, and that making the child an active participant in his or her own rehabilitation program as early as possible will yield comparable benefits.

The tool depicts three different environments: a classroom, a home, and an outdoors area. The child can place moveable figures and everyday objects in the various environments to describe their communication successes and challenges in their everyday life. Thus, the 'My World' tool can help facilitate an understanding of the child's hearing loss from his or her own point of view. By being curious and using open-ended questionning techniques, the professional can guide the child to talk about their communication and develop a shared understanding about aspects of communication that are important to the child.

What are the problems?

For the professionals

- Gaining an accurate picture of the child's communication in real life
 - Information mostly obtained from parents or teachers. Do the parents/teachers really know about the all of a child's communication situations or might they have a different agenda?
 - Inter-agency communication channels not always free-flowing/efficient/effective
 - Timeliness of information
 - Accuracy of information
- Negotiating SMART COSI (Client Orientated Scale of Improvement) goals
 - Often in family-centred care there is a danger that goals are the parents' or teachers' goals
 - Goals focus on academic success and speech and language levels or hearing the 'sss'
 - What is important to the child?
 - . Is there adequate attention to the quaility of life (QoL) and well-being of the child?
- Evaluating intervention to date
- Based on teacher/parental report? Do we ask the child?
- Parents and teachers report on academic success. Does this provide sufficient evidence of successful rehabilitation?
- How do we find the effectiveness of intervention in providing good QoL and well-being to the child? Planning future intervention that addresses things that really matter to the child
 - - Based on COSI goals, do they reflect the real-life needs of the child?
 - Are the interventions specific to the child's needs. For example, are we fitting an FM system 'because it increases the signal-to-noise' or as an integral part of achieving a communication goal that will improve the child's QoL?
- 'Compliance' with rehabilitation
 - Compliance suggests submission, should we be looking for concordance...where the child and the audiologist make decisions together?
 - Would engaging the child to take charge of their own communication needs increase concordance as is the case in adult rehabilitation?
- Looking beyond amplification
- How do we help children to employ effective strategies to use their amplification to communicate effectively? For example, a printed list starting with sit at the front of the class...how much will this impact on a child's communication?
- Self-efficacy...how do we formulate intervention that a child believes that they can implement?

For the child

- Understanding that I am a person and not just a big blob of hearing loss
- Understanding that 'the hearing loss' is responsible for communication difficulties not me
- How do I fit in?...not by always insisting that I sit at the front of the class, and constantly telling the teacher to put the FM on, and by wearing hearing aids that draw attention to my differences.....
- I hate hearing tests, why do I have to go and no-one else does?
- I don't like having that TOD following me around all the time, it looks like I'm a special needs kid...stigma
- Obtaining coping stratergies and emotional support/stratergies

The nine underlying principles in the tool prototype were:

- 1) Enable a patient-centred dialogue
- 2) Provide a supportive environment for children to tell their own experience
- 3) Joint focus and attention on what is relevant to the child
- 4) Discussion led by the family and child, related to their reality
- 5) Externalise issues related to hearing loss
- 6) Provide an insight into positive experiences and challenges faced by the child and family
- 7) Enable audiologists to hear details not usually obtained
- 8) Enable joint goal setting
- 9) Engaging and motivating

It is important to acknowledge that there may be confusion of the roles/processes of the tool in the clinical setting from which the Ida Institute developed the tool, and that the tool may need further refinement. Defined uses for this tool are yet to be established and are a goal of this project to ascertain.

What questions can potentially be addressed using the tool: (This is not a definitive list, and please feel free to comment on your own in the questionnaire).

Audiologist	Psychologist	Teacher of the Deaf
•What are the child's most difficult listening situations? Where are they? Home, school, etc?	•Does the child have good self-esteem?	•How well does the child communicate with their peers?
•Who does the child have trouble communicating with/understanding?	•Does the child have a good self concept?	•What are the main situations where the child has difficulties hearing in the classroom?
•Is the child using their FM successfully in class? Is it helping them?	•Does the child have good self efficacy?	•How effective does the child find their FM system in the classroom?
•How does the child manage with their hearing loss at home?	•How does the child self perceive?	•What are the child's most difficult listening situations? Where are they? Home, school, etc?
•What are the child's communication successes and challenges?	•What are the child's attitudes towards self/others?	•How well does the child communicate with their classroom teacher/s?
•What are the child's limitations with their current amplification?	•What are the child's attitudes towards hearing impairment?	•What are the child's attitudes towards self/others?
•How does the child go about self advocacy? How do they feel about doing this?	•What are the child's attitudes towards their hearing aids/CIs, etc?	•What are the child's positive and negative experiences with having a hearing loss?
•What strategies can help the child in their communication challenges?	•Does the child receive emotional support from their family/friends?	•Does the child self advocate with about their hearing loss?
•How does the child perceive their current amplification (i.e. is it adequate)?	•What are the child's behavioural issues in particular situations?	•How does the child feel others perceive them?
•How does the child manage with their hearing loss with peers?	•What are the child's positive and negative experiences with having a hearing loss?	•Are the current classroom strategies helping the child from their view?
•How does the child perceive their hearing loss?	•What is the psychosocial developmental level of the child?	•What is the child's level of spoken English?
• Find out if child is actually using the amplification, where and when	•What is the child's level of self-reliance?	•Does the child have adequate access to the school curriculum?
• Identify situations where is the child communicating successfully?	•Does the child have a good level of environmental awareness?	 How does the child perceive help from their educational assistant/ interpreter?
 Deconstructing with a child the communication strategies that he or she is already employing successfully 	•Does the child have anxiety in specific situations?	•
Identify communication challenges that are important to the child	•Does the child have an emotional disorder? (e.g. anger/frustration/impulsivity)	
• Are there strategies that the child is already employing successfully in one situation that might help in another?	•Does the child have behavioural control?	
Uncover any maladaptive strategies that need to be addressed?	•How does the child behave non-verbally?	
 Help the child to 're-story' his or her perspective to highlight strengths and successful strategies 		
• Externalise the hearing loss		
• Co-formulate strategic solutions to communication challenges that are practicable		
• Explore self-efficacy issues that may hinder successful employment of communication strategies		
Rehearse self-advocating vocabulary to use in real-life communication situations specific to the child		
Problem-solve new strategies for communication situations that are not working and causing unhappiness		
• Engage the child in his or her own rehabilitation program		
 Evaluation of intervention to date 		
Negotiation of COSI goals to be addressed by future intervention		
Planning of future intervention		

After reading the introduction above and in considering the questions that the tool could be used to address, please firstly look at the tool components:

- 1. MyWorld_Intro_Sheet
- 2. MyWorld_listening_guide
- 3. MyWorld_Documentation_form
- 4. MyWorld_Boards
- 5. MyWorld_All_Items

Then the supporting resources:

- 1. How to use the 'My World' tool during the consultation session
- 2. Introducing the tool
- 3. Methods to record and preserve information
- 4. Responding to the child's story
- 5. Paediatric counselling skills
- 6. Multidisciplinary interventions
- 7. Questions for teens and young adults
- 8. Using the 'My World' tool at different developmental stages
- 9. Functional skill screening tool 'My World'

And then watch the videos of the tool in use in the following order:

- 1. 'My World' Instructional Video by Ida
- 2. Kathleen and her family Video
- 3. Development of the Tool A
- 4. Development of the Tool B
- 5. Tool in Use MyWorld_Ariana_Classroom
- 6. Tool in Use MyWorld_Emily_Classroom
- 7. Tool in Use MyWorld_Ashlynn_Outside
- 8. Tool in Use MyWorld_Amber_Classroom
- 9. Tool in Use MyWorld_Chloe_Home

It is important to note that these videos do not demonstrate perfect use of how to use the 'My World' tool, and some may be quite poor examples. Please examine them, and keep in mind what would constitute a good instructional video and whether this would be useful if you were to use the tool.

To access the tool components, supporting resources, and the videos: After you have signed and returned the video consent form and the participation consent form to the researcher via email (20351824@student.uwa.edu.au) you will be emailed a link to an Australian Hearing shared drive.

Please note that it is a condition of your participation in this project that downloading, saving or distribution of the videos is not consented.

Any questions or difficulties with the viewing of the videos or any of the material please email: 20351824@student.uwa.edu.au

Below is a brief case history for each of the tool in use and the Kathleen and her family videos:

Kathleen and her family

- It appears Kathleen's parents had a difficult time understanding and coming to grips with Kathleen's hearing loss. Kathleen experienced bouts of depression and loneliness during her youth, but Kathleen's parents remained frozen. The family did not openly discuss Kathleen's situation or take concrete action to reach out to Kathleen and assess how she was dealing with her hearing loss.
- This story highlights the enormous value of encouraging families to openly discuss hearing loss and creating a space for that discussion to occur. The consequences of hearing loss can be described in terms of decibels and frequencies, but also in terms of social and emotional aftershocks. While it is not possible to address all issues related to hearing loss, it is important that one remembers to treat the whole patient, the whole family, and not just the hearing loss itself.

Tool in Use - MyWorld Ariana Classroom

- Ariana is nine years old and has bilateral cochlear implants. She received her first implant when she was three years old and her second at the age of seven.
- She attends a centre-based school where she is using both sign language and speech to communicate. According to Nanette, Ariana's audiologist, Ariana has made tremendous progress with her listening skills during the past several years, but she is not confident in her listening abilities.

- Using the 'My World' tool, Nanette was surprised to learn that Ariana does not feel like she can listen and understand the classroom teacher. Nanette was aware that Ariana uses an interpreter at times, but did not know that she relies on sign language as her primary mode of comprehending classroom content. Further, Nanette says she had hoped that Ariana was more comfortable advocating for herself and relating to her teachers.
- As a result of the 'My World' experience, self-advocacy has been highlighted as an objective for her at school and at home.

Tool in Use - MyWorld Emily Classroom

- Emily is a 7-year-old girl with Treacher Collins Syndrome. Emily's has a bilateral conductive hearing loss and uses an implanted bone conduction device on one ear and a hearing aid on the other ear.
- Emily's audiologic care was complicated due to a significant phobia for medical services that developed around 2 years of age. Using the 'My World' tool at visits when she was 5 and 6 years of age has allowed Emily to share her perspectives through imaginative play.
- Emily's audiologist has used the tool twice with her, exploring communication in the home setting and to teach her more about Emily's communication partners at school.
- Emily's Audiologist has been able to use the information gained through both sessions to develop strategies in terms of behaviour changes and using technology to enhance Emily's communication skills in different settings.

Tool in Use - MyWorld_Ashlynn_Outside

- Ashlynn was 9 years old when she was filmed using the 'My World' Tool. She has a bilateral, moderately-severe, sensorineural hearing loss that was not diagnosed until she was 4 years of age.
- Her hearing care professional used the 'My World' tool to facilitate a discussion of her relationship with her younger sister. Her younger sister was diagnosed with hearing loss and there was a need to explore their relationship and how Ashlynn could support her sister's use of technology.
- Through their discussion, Ashlynn's Audiologist learned a lot about how Ashlynn handles relationships. This has opened up the opportunity for them to explore how her impaired communication skills impact her relationships. It also allowed her to discuss how Ashlynn can support her sister and family in using more effective communication strategies.

Tool in Use - MyWorld Amber_Classroom

- Amber recently attended a full hearing aid review appointment and underwent full audiometric testing, hearing aid fine tuning and aided assessment. This has addressed her audiological needs quite effectively, says Richard, Amber's hearing care professional.
- In paediatric appointments, Richard often experiences that the parents share information based on their experiences and observations of aided performance at home, in social situations, and on professional reports from teachers at school and teachers of the deaf.
- Richard felt that using the 'My World' Tool helped shift the focus back onto Amber and gave her a free forum with which she could express how she coped in the school environment.

Tool in Use - MyWorld_Chloe_Home

- Chloe has been using hearing aids effectively for the last five years. She has regular contact with her Teacher of the Deaf in school and is a 'model' hearing aid and FM user.
- As she is managing so well at school, Chloe's hearing care professional, Richard, decided to explore her home environment using the 'My World' tool. In the past, Chloe has been fairly shy in the clinic and has not expressed any difficulty at home or in social situations.
- The session with the tool not only revealed the difficulties she experiences with communication at home, but also enabled Chloe's parents to realize how many situations, which are often taken for granted, pose real communication difficulties for her.
- Richard feels that the session helped Chloe's parents gain a better understanding of her difficulties but also aided him in being able to tailor her hearing aid management and counselling appropriately.

Following the viewing of the videos please fill out the accompanying questionnaire, email it to:

20351824@student.uwa.edu.au

Thank you for your time and participation in this research project. Jessica Round Master of Clinical Audiology Student University of Western Australia APPENDIX (B) - AUDIOLOGIST QUESTIONNAIRE

Paediatric Audiologist Questionnaire

The Need and Uses of the Ida 'My World' Counselling Tool in Paediatric Rehabilitation for Hearing-impaired Children

- 1. What was your first reaction to the tool? Click here to enter text.
- 2. The 'My World' tool was conceived during a brainstorming focus group in Denmark...'to give the child a voice'. The reactions to the tool are very mixed, varying from:

"....it's the best innovation I've seen for years in paediatric rehabilitation..."

to

"...without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain..."

It appears that this new tool challenges the role of an audiologist. How do you feel about these comments?

Click here to enter text.

3. What is your current method of obtaining information from the child's perspective of their hearing loss in a paediatric session? (i.e. talking to the child/ talking to the parent/obtaining information from their classroom or Visiting Teacher of the Deaf?)

Click here to enter text.

4. Tell me about the information-gathering process you use to evaluate how well a hearing impaired child is managing to go about his or her daily life with hearing loss, at home, at school and in social situations?

Click here to enter text.

5. Please rate the following aspects of the videos (please <u>click</u> the box you agree with – <u>select only one</u>):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The instructional video was useful					
The instructional video needs more information on how and when to use the tool, and its particular uses					
The tool was adequately thought through in its development					
The Kathleen and her family video was very relevant and highlights the need for the My World tool					
The tool in use videos showed a good example of the tool's use					
The Audiologists needed more training on using the tool					
It is evident that good knowledge of counselling skills are necessary to be able to use the tool					
The Audiologists effectively engaged the children using the tool					
Use of the tool allowed the Audiologist to gain meaningful information about the child's perspective of their hearing loss					
Engagement of the child took some time before useful information was elicited					
I feel that a better and more informative instructional video would help me if I was to use this tool clinically					

6. If you have any other comments about the videos, please discuss them below.

Click here to enter text.

7.

Please rate the following aspects of paediatric rehabilitation and your counselling skills (please <u>click</u> the box you agree with – <u>select only one, EXCEPT THE LAST QUESTION WHERE YOU MAY</u> <u>SELECT MORE THAN ONE</u>):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Patient-centred care (as used in adult rehabilitation) which the tool uses, is compatible with family-centred care in paediatric audiology					
There is a gap in my knowledge about hearing loss from the child's perspective					
Current methods for counselling of hearing-impaired children are adequate					
There needs to be an alternative method for counselling hearing- impaired children					
Knowledge of psychology counselling skills (e.g. narrative or play therapy) would be useful in using this tool clinically					
Scenarios on how to use the tool to obtain certain information (e.g. the questions on the summary handout) would be useful clinically					
The tool is within the boundary of audiology expertise in rehabilitation					
I feel counselling hearing-impaired children is within the scope of my audiological practice					
I would feel comfortable with a counselling role in the rehabilitation of hearing-impaired children					
I feel that this counselling tool would enable me to help a hearing- impaired child to externalise their hearing loss and obtain the child's narrative					
I have a good understanding of Erik Erikson's stages of psychosocial development					
I have a good understanding of the psychosocial features of hearing-impaired children					
I know how to effectively counsel each stage of psychosocial development in hearing-impaired children					
I have a good understanding of Jean Piaget's theory of intellectual and perceptual development					
I have a good understanding on how Jean Piaget's theory of intellectual and perceptual development relates to the psychosocial difficulties experienced by hearing-impaired children					
I can effectively counsel mainstreamed hearing-impaired children about school issues					
I have a good grasp on whether to refer a hearing-impaired child to a psychologist or counsellor and how to go about this					
I received training on counselling skills at university					
	Audiologist	Psychologist	Teacher of the Deaf	All three	Other (please specify)
Who should address the counselling needs of hearing-impaired children					

8. Tell me about your level of education, e.g. Audiology qualifications, and if you have received extra training/degrees in counselling/teaching, etc.

Click here to enter text.

9. Please rate the following aspects of The 'My World' Tool (please <u>click</u> the box/es you agree with – you may select more than one):

	3-5 years	6-9 years	10-12 years	3-12 years	Other (please write)
The most appropriate age group for the tool is:					Click here to enter text.

	Screening and Referral (e.g. to Psychologist)	Counselling on hearing strategies, social-emotional counselling	Both	Other (please write)	There is no use clinically for the tool in practice
The tool should be used by Audiologists for:					

	Annual Reviews	Hearing Aid Reviews	Cochlear implantation or other candidacy assessments	Periodic educational assessments	Other (please write)
When and under what circumstances should the My World Tool be used:					Click here to enter text.

10. What other uses do you potentially see for this tool in rehabilitation?

Click here to enter text.

11. Please rate the following aspects of The 'My World' Tool (please <u>click</u> the box/es you agree with – you may select more than one):

	Audiologist	Psychologist	Teacher of the Deaf/Visiting Teacher	All of the selection	None
Who do you think should be using this tool					

12. Do you think parents could have a role in the use of this tool? e.g. Filial therapy? (Filial therapy is a closely related form of child-centred play therapy that involves the parents or carers). Why/Why not?

Click here to enter text.

13. Please rate the following aspects of The 'My World' Tool (please <u>click</u> the box you agree with – <u>select only one</u>):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
More information is needed on <u>when</u> to introduce the tool					
More information is needed on <u>how</u> to introduce the tool (i.e. there is a need for alternative possible processes)					
It is clear how to use the tool during a consultation session					
The example questions to ask are helpful					
More example questions and scenarios are needed					
The questions to ask need to be more refined to obtain specific information from the child (i.e. for different situations that the tool can be used to address)					
The tool items are adequate in number and form					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The packaging of the tool should be different for different age groups (i.e. customisation and item units)					
The tool needs more development overall					
A multi-disciplinary approach is needed in the use of this tool					
The documentation form is adequate					
The documentation form needs refining/is too vague					
There is a use for the My World Tool clinically					
This tool could enhance/improve the outcomes of paediatric rehabilitation					
This tool would be useful in obtaining BOTH the child's perspective of their hearing loss and helping the child successfully					
The tool could work well using photos for inspiration					
Open-ended questions work well with this tool					
The methods to record and preserve information needs refining if the tool is to be used clinically					
This tool will increase the effectiveness of counselling by Audiologists for hearing-impaired children					
I feel that this tool would be a useful counselling tool with hearing- impaired children who have very limited language					
I feel that narrative and play therapy techniques would be useful knowledge if I was to use this tool clinically					
I feel that more paediatric counselling skill resources are necessary					
The suggestions for the use of the tool at different stages of development are helpful but need further development					
The questions suggested for teens and young adults were helpful and informative					
The functional skills screening tool would be very useful to use in conjunction with the My World Tool in examining the domains of cognitive, behavioural, social, self-advocacy, communication, physical, language, speech intelligibility, and auditory and listening skills					

14. Would you feel comfortable counselling hearing impaired children using a tool in their rehabilitation?

Click here to enter text.

15. Please rate the following aspects of The 'My World' Tool (please <u>click</u> the box you agree with – <u>select only one</u>):

	YES	NO	UNSURE
Would you use this tool clinically as it is currently presented			

Appointment time constraints	
No clear instruction on how to use it clinically	
Unsure whether I would be able to gather useful information	
Current clinical methods in obtaining this information is effective	
Other (please describe)	
Click here to enter text.	

16. Do you think such a tool would be successful for bridging the gap between the roles of audiologists and psychologists? Why/why not?

Click here to enter text.

17. How can this tool be framed so that it is more intuitive for a Paediatric Audiologist to use?

Click here to enter text.

18. Do you see different or more specific ways this tool could be incorporated clinically? Or uses for this tool by other professionals?

Click here to enter text.

19. What additional skills or resources do you feel could enhance this role in the rehabilitation of hearing impaired children?

Click here to enter text.

20. What questions can potentially be addressed by using the tool? If you can think of further questions in addition to those on the summary form please note them below.

Click here to enter text.

Thank you for completing this questionnaire and for your participation in this research project.

Please email the completed questionnaire to 20351824@student.uwa.edu.au

APPENDIX (C) – SUMMARY FOR AUDIOLOGISTS, PSYCHOLOGISTS AND TEACHERS OF THE DEAF

The Need and Uses of the Ida 'My World' Counselling Tool in Paediatric Rehabilitation for Hearing-impaired Children

Jessica Round, Master of Clinical Audiology, Supervisor – Karen Parfitt & Dr Robert Patuzzi

Introduction: Because of their reduced vocabulary and communication skills, a child with a severe hearing loss can be at a great disadvantage in explaining to parents, teachers and professionals the problems they face day to day. The 'My World' tool, which is being developed at the Ida Institute, Denmark in collaboration with professionals from the US and the UK, is intended to be used during a consultation session to support a dialogue about communication situations between a professional and a young child. The tool is employing natural play, to enable a child to express actions, thoughts and concerns around communication situations in their lives, and providing the necessary physical objects to enable the child to problem solve and formulate logical solutions.

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The tool depicts three different environments: a classroom, a home, and an outdoors area. The child can place moveable figures and everyday objects in the various environments to describe their communication successes and challenges in their everyday life. Thus, the 'My World' tool can help facilitate an understanding of the child's hearing loss from his or her own point of view. By being curious and using open-ended questionning techniques, the professional can guide the child to talk about their communication and develop a shared understanding about aspects of communication that are important to the child.

What are the problems? For the professionals

- Gaining an accurate picture of the child's communication in real life
 - Information mostly obtained from parents or teachers. Do the parents/teachers really know about the all
 of a child's communication situations or might they have a different agenda?
 - Inter-agency communication channels not always free-flowing/efficient/effective
 - Timelyness of information
 - Accuracy of information
- Negotiating SMART COSI (Client Orientated Scale of Improvement) goals
 - Often in family-centred care there is a danger that goals are the parent's or teachers' goals
 - Goals focus on academic success and speech and language levels or hearing the 'sss'
 - What is important to the child?
 - Is there adequate attention to the quaility of life (QoL) and well-being of the child?
- Evaluating intervention to date
- Based on teacher/parental report? Do we ask the child?
- Parents and teachers report on academic success. Does this provide sufficient evidence of successful rehabilitation?
- How do we find the effectiveness of intervention in providing good QoL and well-being to the child?
- Planning future intervention that addresses things that really matter to the child
 - Based on COSI goals, do they reflect the real-life needs of the child?
 - Are the interventions specific to the child's needs. For example, are we fitting an FM system 'because it increases the signal-to-noise' or as an integral part of achieving a communication goal that will improve the child's QoL?
- 'Compliance' with rehabilitation
 - Compliance suggests submission, should we be looking for concordance...where the child and the audiologist make decisions together?
 - Would engaging the child to take charge of their own communication needs increase concordance as is the case in adult rehabilitation?

• Looking beyond amplification

- How do we help children to employ effective strategies to use their amplification to communicate effectively? For example, a printed list starting with sit at the front of the class...how much will this impact on a child's communication?
- Self-efficacy...how do we formulate intervention that a child believes that they can implement?

For the child

- Understanding that I am a person and not just a big blob of hearing loss
- Understanding that 'the hearing loss' is responsible for communication difficulties not me
- How do I fit in?...not by always insisting that I sit at the front of the class, and constantly telling the teacher to put the FM on, and by wearing hearing aids that draw attention to my differences.....
- I hate hearing tests, why do I have to go and no-one else does?
- I don't like having that TOD following me around all the time, it looks like I'm a special needs kid...stigma
- Obtaining coping stratergies and emotional support/stratergies

The nine underlying principles in the tool prototype were:

- 1) Enable a patient-centred dialogue
- 2) Provide a supportive environment for children to tell their own experience
- 3) Joint focus and attention on what is relevant to the child
- 4) Discussion led by the family and child, related to their reality
- 5) Externalise issues related to hearing loss
- 6) Provide an insight into positive experiences and challenges faced by the child and family
- 7) Enable audiologists to hear details not usually obtained
- 8) Enable joint goal setting
- 9) Engaging and motivating

It is important to acknowledge that there may be confusion of the roles/processes of the tool in the clinical setting from which the Ida Institute developed the tool, and that the tool may need further refinement. Defined uses for this tool are yet to be established and are a goal of this project to ascertain.

What questions can potentially be addressed using the tool: (This is not a definitive list, and please feel free to add you own for discussion in the
interview).

Audiologist	Psychologist	Teacher of the Deaf		
•What are the child's most difficult listening situations? Where are they? Home, school, etc?	•Does the child have good self-esteem?	•How well does the child communicate with their peers?		
•Who does the child have trouble communicating with/understanding?	•Does the child have a good self concept?	•What are the main situations where the child has difficulties hearing in the classroom?		
• Is the child using their FM successfully in class? Is it helping them?	•Does the child have good self efficacy?	•How effective does the child find their FM system in the classroom?		
•How does the child manage with their hearing loss at home?	•How does the child self perceive?	•What are the child's most difficult listening situations? Where are they? Home, school, etc?		
•What are the child's communication successes and challenges?	•What are the child's attitudes towards self/others?	•How well does the child communicate with their classroom teacher/s?		
•What are the child's limitations with their current amplification?	•What are the child's attitudes towards hearing impairment?	•What are the child's attitudes towards self/others?		
•How does the child go about self advocacy? How do they feel about doing this?	•What are the child's attitudes towards their hearing aids/CIs, etc?	•What are the child's positive and negative experiences with having a hearing loss?		
•What strategies can help the child in their communication challenges?	•Does the child receive emotional support from their family/friends?	•Does the child self advocate with about their hearing loss?		
•How does the child perceive their current amplification (i.e. is it adequate)?	•What are the child's behavioural issues in particular situations?	•How does the child feel others perceive them?		
•How does the child manage with their hearing loss with peers?	•What are the child's positive and negative experiences with having a hearing loss?	•Are the current classroom strategies helping the child from their view?		
•How does the child perceive their hearing loss?	•What is the psychosocial developmental level of the child?	•What is the child's level of spoken English?		
• Find out if child is actually using the amplification, where and when	•What is the child's level of self-reliance?	•Does the child have adequate access to the school curriculum?		
• Identify situations where is the child communicating successfully?	•Does the child have a good level of environmental awareness?	 How does the child perceive help from their educational assistant/ interpreter? 		
• Deconstructing with a child the communication strategies that he or she is already employing successfully	•Does the child have anxiety in specific situations?	•		
Identify communication challenges that are important to the child	•Does the child have an emotional disorder? (e.g. anger/frustration/impulsivity)			
 Are there strategies that the child is already employing successfully in one situation that might help in another? 	•Does the child have behavioural control?			
• Uncover any maladaptive strategies that need to be addressed?	•How does the child behave non-verbally?			
 Help the child to 're-story' his or her perspective to highlight strengths and successful strategies 				
• Externalise the hearing loss				
 Co-formulate strategic solutions to communication challenges that are practicable 				
 Explore self-efficacy issues that may hinder successful employment of communication strategies 				
Rehearse self-advocating vocabulary to use in real-life communication situations specific to the child				
 Problem –solve new strategies for communication situations that are not working and causing unhappiness 				
• Engage the child in his or her own rehabilitation program				
 Evaluation of intervention to date 				
Negotiation of COSI goals to be addressed by future intervention				
Planning of future intervention				

After reading the introduction above and in considering the questions that the tool could be used to address, please firstly look at the tool components located in the box:

- 1. Introduction Sheet
- 2. Listening Guide
- 3. Documentation Form
- 4. Examine the boards and the movable items

Then please read the supporting resources located in the box:

- 1. How to use the 'My World' tool during the consultation session
- 2. Introducing the tool
- 3. Methods to record and preserve information
- 4. Responding to the child's story
- 5. Paediatric counselling skills
- 6. Multidisciplinary interventions
- 7. Questions for teens and young adults
- 8. Using the 'My World' tool at different developmental stages
- 9. Functional skill screening tool 'My World'

Now please watch the videos of the tool in use in the following order on the USB supplied to you:

- 1. 'My World' Instructional Video by Ida
- 2. Kathleen and her family Video
- 3. Development of the Tool A
- 4. Development of the Tool B
- 5. Tool in Use MyWorld_Ariana_Classroom
- 6. Tool in Use MyWorld_Emily_Classroom
- 7. Tool in Use MyWorld_Ashlynn_Outside
- 8. Tool in Use MyWorld_Amber_Classroom
- 9. Tool in Use MyWorld_Chloe_Home

It is important to note that these videos do not demonstrate perfect use of how to use the 'My World' tool, and some may be quite poor examples. Please examine them, and keep in mind what would constitute a good instructional video and whether this would be useful if you were to use the tool.

Below is a brief case history for each of the tool in use and the Kathleen and her family videos:

Kathleen and her family

- It appears Kathleen's parents had a difficult time understanding and coming to grips with Kathleen's hearing loss. Kathleen experienced bouts of depression and loneliness during her youth, but Kathleen's parents remained frozen. The family did not openly discuss Kathleen's situation or take concrete action to reach out to Kathleen and assess how she was dealing with her hearing loss.
- This story highlights the enormous value of encouraging families to openly discuss hearing loss and creating a space for that discussion to occur. The consequences of hearing loss can be described in terms of decibels and frequencies, but also in terms of social and emotional aftershocks. While it is not possible to address all issues related to hearing loss, it is important that one remembers to treat the whole patient, the whole family, and not just the hearing loss itself.

Tool in Use - MyWorld_Ariana_Classroom

- Ariana is nine years old and has bilateral cochlear implants. She received her first implant when she was three years old and her second at the age of seven.
- She attends a centre-based school where she is using both sign language and speech to communicate. According to Nanette, Ariana's audiologist, Ariana has made tremendous progress with her listening skills during the past several years, but she is not confident in her listening abilities.
- Using the 'My World' tool, Nanette was surprised to learn that Ariana does not feel like she can listen and understand the classroom teacher. Nanette was aware that Ariana uses an interpreter at times, but did not know that she relies on sign language as her primary mode of comprehending classroom content. Further, Nanette says she had hoped that Ariana was more comfortable advocating for herself and relating to her teachers.
- As a result of the 'My World' experience, self-advocacy has been highlighted as an objective for her at school and at home.

Tool in Use - MyWorld Emily Classroom

- Emily is a 7-year-old girl with Treacher Collins Syndrome. Emily's has a bilateral conductive hearing loss and uses an implanted bone conduction device on one ear and a hearing aid on the other ear.
- Emily's audiologic care was complicated due to a significant phobia for medical services that developed around 2 years of age. Using the 'My World' tool at visits when she was 5 and 6 years of age has allowed Emily to share her perspectives through imaginative play.
- Emily's audiologist has used the tool twice with her, exploring communication in the home setting and to teach her more about Emily's communication partners at school.
- Emily's Audiologist has been able to use the information gained through both sessions to develop strategies in terms of behaviour changes and using technology to enhance Emily's communication skills in different settings.

Tool in Use - MyWorld_Ashlynn_Outside

- Ashlynn was 9 years old when she was filmed using the 'My World' Tool. She has a bilateral, moderately-severe, sensorineural hearing loss that was not diagnosed until she was 4 years of age.
- Her hearing care professional used the 'My World' tool to facilitate a discussion of her relationship with her younger sister. Her younger sister was diagnosed with hearing loss and there was a need to explore their relationship and how Ashlynn could support her sister's use of technology.
- Through their discussion, Ashlynn's Audiologist learned a lot about how Ashlynn handles relationships. This has opened up the opportunity for them to explore how her impaired communication skills impact her relationships. It also allowed her to discuss how Ashlynn can support her sister and family in using more effective communication strategies.

Tool in Use - MyWorld Amber Classroom

- Amber recently attended a full hearing aid review appointment and underwent full audiometric testing, hearing aid fine tuning and aided assessment. This has addressed her audiological needs quite effectively, says Richard, Amber's hearing care professional.
- In paediatric appointments, Richard often experiences that the parents share information based on their experiences and observations of aided performance at home, in social situations, and on professional reports from teachers at school and teachers of the deaf.
- Richard felt that using the 'My World' Tool helped shift the focus back onto Amber and gave her a free forum with which she could express how she coped in the school environment.

Tool in Use - MyWorld_Chloe_Home

- Chloe has been using hearing aids effectively for the last five years. She has regular contact with her Teacher of the Deaf in school and is a 'model' hearing aid and FM user.
- As she is managing so well at school, Chloe's hearing care professional, Richard, decided to explore her home environment using the 'My World' tool. In the past, Chloe has been fairly shy in the clinic and has not expressed any difficulty at home or in social situations.
- The session with the tool not only revealed the difficulties she experiences with communication at home, but also enabled Chloe's parents to realize how many situations, which are often taken for granted, pose real communication difficulties for her.
- Richard feels that the session helped Chloe's parents gain a better understanding of her difficulties but also aided him in being able to tailor her hearing aid management and counselling appropriately.

Following the viewing of this material, an interview with you will follow within a week and should take no longer than 1 hour. Please bring the 'My World' tool and the USB to the interview.

Thank you for your time and participation in this research project.

Jessica Round

Master of Clinical Audiology Student

University of Western Australia

APPENDIX (D) – INTERVIEW QUESTIONS FOR AUDIOLOGISTS

INTRO Questions

- What was your first reaction to the tool?
- The 'My World' tool was conceived in a brainstorming focus group in Denmark...'to give the child a voice'. The reactions to it are very mixed, varying from:

"...it's the best innovation I've seen for years in paediatric rehabilitation ... "

to

"...without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain..."

It appears that this new tool challenges the role of an audiologist. How do you feel about these comments?

- What is your current method of obtaining information from the child's perspective of their hearing loss in a paediatric session? (i.e. talking to the child/ talking to the parent/obtaining information from their classroom or Visiting Teacher of the Deaf?)
- Tell me about the information-gathering process you use to evaluate how well a hearing impaired child is managing to go about his or her daily life with hearing loss, at home, at school and in social situations?

VIDEO Questions

- Was the instructional video useful or do you think there needs to be one that shows you how to use the tool in more detail e.g. for different situations?
- Was the Kathleen and her family video very relevant and does it highlight a need for this tool?
- What is your opinion on the videos of the tool in use? Did they show good use of the tool? Please elaborate.
- Do you think the Audiologists needed more training on using the tool, so it was intuitive to use?
- Did you think that the tool allowed the Audiologists to obtain meaningful information about the child's perspective of their hearing loss? Why/Why not?
- Do you have any other comments about the videos?

PAEDIATRIC REHABILITATION AND COUNSELLING SKILLS

- To what extent do you feel that counselling hearing-impaired children should be within the scope of audiology practice?
- In paediatric audiology, following work from many such as Luterman, we focus on family-centred care. In adult rehabilitation, we know that patient-centred care leads to optimal outcomes for the adult. When should we be transitioning from family-centred...looking after the interests of the family...to patient-centred care...putting the interests of the child first? Or are the two compatible?

- Would you feel comfortable counselling hearing impaired children using a tool in their rehabilitation?
- Do you perceive a gap between the counselling by an Audiologist and a Psychologist? Do you think such a tool would be successful for bridging the gap between the roles of audiologists and psychologists? Why/why not?
- Do you perceive a gap in understanding the child's perspective of their hearing loss?
- Do you have knowledge of Erik Erikson's stages of psychosocial development and Jean Piaget's theory of intellectual and perceptual development and how these relate to the psychosocial features of hearing-impaired children?
- Have you had any extra training in counselling or psychology?
- Do you feel there needs to be an alternative method for the counselling of hearing impaired children or do you feel current methods are effective? Are there issues that are not addressed with current clinical methods? Why/Why not? How/How not? Do you think these current methods could be combined with the 'My World' tool?
- Who do you think should address the counselling needs of hearing-impaired? Audiologists? Psychologists? Teacher of the Deaf? All? Others?

The 'My World' tool itself Questions

- Do you think knowledge of psychology counselling skills (e.g. narrative or play therapy) would be useful in using this tool clinically?
- Would scenarios on how to use the tool to obtain certain information (e.g. questions on the summary sheet) be useful?
- Do you think it is clear on how to use the tool as it is currently presented?
- Do you think the tool needs more development? How about the tool items? Are they adequate in number and form?
- What age do you think is the most appropriate for the 'My World' tool? That is, what age of child will respond well to this tool/to assist hearing impaired children in different psychosocial stages of development? A particular age or range of age? should the packaging be different for different age groups?
- What is your opinion on the suggestions for use at different psychosocial stages of development? (show the page to interviewee as prompt)? What about the suggestion of the functional skills screening tool?
- Who do you think the tool should be used by? Audiologists? Psychologists? Teacher of the Deaf? All? Others?
- What do you think the tool should be used for by Audiologists? e.g. screening and referral, counselling on hearing strategies/social-emotional wellbeing, both, others?
- When and what circumstances should the 'My World' tool be used? e.g. annual reviews, hearing aid reviews, cochlear implantation or other candidacy assessments, periodic educational assessments, other?
- What is your opinion on the documentation form? Is it too vague?
- Do you have any comment on the supporting documents?
- Would you use the tool clinically as it is currently presented? Why/why not?
- Do you think there is a use for the Ida 'My World' tool in audiology sessions with hearing-impaired children? Do you think it is necessary and helpful? What issues do you see with it being used clinically?
- Do you think parents could have a role in the use of this tool? e.g. Filial therapy? Why/why not?

- Do you think this tool could this enhance/improve the outcomes of paediatric rehabilitation?
- What kind of uses in rehabilitation could this tool be useful for? What other uses do you potentially see for this tool in rehabilitation? Specific uses?
- Would this tool be useful for obtaining both the child's perspective of their hearing loss and helping the child? How can it be framed so that it is more intuitive for a Paediatric Audiologist to use?
- Do you see any other uses for this tool by other professionals? Do you see different ways this tool could be used clinically as an audiologist?
- What additional skills or resources do you feel could enhance this role in the rehabilitation of hearing impaired children? What questions do you think can potentially be addressed by using the tool? If you can think of any further questions in addition to those on the summary form please describe? How could the tool be adapted to show how Audiologists/Professionals how to obtain such information in a clinical session?

APPENDIX (E) – INTERVIEW QUESTIONS FOR TEACHERS OF THE DEAF

INTRO Questions

- What was your first reaction to the tool?
- The 'My World' tool was conceived in a brainstorming focus group in Denmark...'to give the child a voice'. The reactions to it are very mixed, varying from:

"...it's the best innovation I've seen for years in paediatric rehabilitation ... "

to

"...without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain..."

It appears that this new tool challenges the role of audiologists. How do you feel about these comments?

- What is your current method of obtaining information from the child's perspective of their hearing loss? (i.e. talking to the child/ talking to the parent/obtaining information from their classroom or Visiting Teacher of the Deaf?)
- Tell me about the information-gathering process you use to evaluate how well a hearing impaired child is managing to go about his or her daily life with hearing loss, at home, at school and in social situations?

VIDEO Questions

- Was the instructional video useful or do you think there needs to be one that shows you how to use the tool in more detail e.g. for different situations?
- Was the Kathleen and her family video very relevant and does it highlight a need for this tool?
- What is your opinion on the videos of the tool in use? Did they show good use of the tool? Please elaborate.
- Do you think the Audiologists needed more training on using the tool, so it was intuitive to use?
- Did you think that the tool allowed the Audiologists to obtain meaningful information about the child's perspective of their hearing loss? Why/Why not?
- Do you have any other comments about the videos?

PAEDIATRIC REHABILITATION AND COUNSELLING SKILLS

- To what extent do you feel that counselling hearing-impaired children should be within the scope of TOD practice?
- In paediatric audiology, following work from many such as Luterman, we focus on family-centred care. In adult rehabilitation, we know that patient-centred care leads to optimal outcomes for the adult. When should we be transitioning from family-centred...looking after the interests of the family...to patient-centred care...putting the interests of the child first? Or are the two compatible?

- Would you feel comfortable counselling hearing impaired children using a tool in their rehabilitation?
- Do you perceive a gap between the counselling by a TOD, Audiologist and a Psychologist? Do you think such a tool would be successful for bridging the gap between the roles of these professionals? Why/why not?
- Do you feel you have a good understanding of hearing loss from the child's perspective? Or do you feel this is a 'gap' is helping hearing impaired children?
- Do you feel that counselling hearing impaired children should be within the scope of Teacher of the Deaf/Visiting Teacher practice? Or that it is/should be within the scope of audiology/psychology?
- Do you have knowledge of Erik Erikson's stages of psychosocial development and Jean Piaget's theory of intellectual and perceptual development and how these relate to the psychosocial features of hearing-impaired children?
- Have you had any extra training in counselling or psychology?
- Do you feel there needs to be an alternative method for the counselling of hearing impaired children or do you feel current methods are effective? Are there issues that are not addressed with current clinical methods? Why/Why not? How/How not? Do you think these current methods could be combined with the 'My World' tool?
- Who do you think should address the counselling needs of hearing-impaired? Audiologists? Psychologists? Teacher of the Deaf? All? Others?

The 'My World' tool itself Questions

- Do you think knowledge of psychology counselling skills (e.g. narrative or play therapy) would be useful in using this tool clinically?
- Would scenarios on how to use the tool to obtain certain information (e.g. questions on the summary sheet) be useful?
- Do you think it is clear on how to use the tool as it is currently presented?
- Do you think the tool needs more development? How about the tool items? Are they adequate in number and form?
- What age do you think is the most appropriate for the 'My World' tool? That is, what age of child will respond well to this tool/to assist hearing impaired children in different psychosocial stages of development? A particular age or range of age? should the packaging be different for different age groups?
- What is your opinion on the suggestions for use at different psychosocial stages of development? (show the page to interviewee as prompt)? What about the suggestion of the functional skills screening tool?
- Who do you think the tool should be used by? Audiologists? Psychologists? Teacher of the Deaf? All? Others?
- What do you think the tool should be used for by Teachers of the Deaf? e.g. screening and referral, counselling on hearing strategies/social-emotional wellbeing, both, others?
- When and what circumstances should the 'My World' tool be used?
- What is your opinion on the documentation form? Is it too vague?
- Do you have any comment on the supporting documents?
- Would you use the tool clinically as it is currently presented? Why/why not?
- Do you think there is a use for the Ida 'My World' tool in Teacher of the Deaf/Visiting Teacher sessions with hearing-impaired children? What is your view on such a tool? Do you think it is necessary and helpful? What issues do you see with it being used?

- Do you think parents could have a role in the use of this tool? e.g. Filial therapy? Why/why not?
- Do you think this tool could this enhance/improve the outcomes of paediatric rehabilitation?

What kind of uses in rehabilitation could this tool be useful for? What other uses do you potentially see for this tool in rehabilitation? Specific uses by TODs? Do you see different ways this tool could be used by Teachers of the Deaf/Visiting Teachers?

- Would this tool be useful for obtaining both the child's perspective of their hearing loss and helping the child? How can it be framed so that it is more intuitive to use?
- Do you see any other uses for this tool by other professionals?

What additional skills or resources do you feel could enhance this role in the rehabilitation of hearing impaired children?

• What questions do you think can potentially be addressed by using the tool? If you can think of any further questions in addition to those on the summary form please describe? How could the tool be adapted to show TODs/ other Professionals how to obtain such information in a clinical session?

APPENDIX (F) – INTERVIEW QUESTIONS FOR PSYCHOLOGISTS

INTRO Questions

- What was your first reaction to the tool?
- The 'My World' tool was conceived in a brainstorming focus group in Denmark...'to give the child a voice'. The reactions to it are very mixed, varying from:

"...it's the best innovation I've seen for years in paediatric rehabilitation ... "

to

"...without audibility our hearing impaired children have no chance of managing hearing loss effectively. We have limited time to gain information from a child, in order to spend time trying to use this new tool, we would have to sacrifice the critical audiometric information that we are trained to obtain..."

It appears that this new tool challenges the role of an audiologist. How do you feel about these comments?

- What is your current method of obtaining information from the child's perspective of their hearing loss in a paediatric session? (i.e. talking to the child/ talking to the parent/obtaining information from their classroom or Visiting Teacher of the Deaf?)
- Tell me about the information-gathering process you use to evaluate how well a hearing impaired child is managing to go about his or her daily life with hearing loss, at home, at school and in social situations?

VIDEO Questions

- Was the instructional video useful or do you think there needs to be one that shows you how to use the tool in more detail e.g. for different situations?
- Was the Kathleen and her family video very relevant and does it highlight a need for this tool?
- What is your opinion on the videos of the tool in use? Did they show good use of the tool? Please elaborate.
- Do you think the Audiologists needed more training on using the tool, so it was intuitive to use?
- Did you think that the tool allowed the Audiologists to obtain meaningful information about the child's perspective of their hearing loss? Why/Why not?
- Do you have any other comments about the videos?

PAEDIATRIC REHABILITATION AND COUNSELLING SKILLS

- To what extent do you feel that counselling hearing-impaired children should be within the scope of audiology or teacher of the deaf practice? i.e. Do you feel that counselling hearing impaired children should be within the scope of mainly psychology, teacher of the deaf or audiology practice or all?
- In paediatric audiology, following work from many such as Luterman, we focus on family-centred care. In adult rehabilitation, we know that patient-centred care leads to optimal outcomes for the adult. When should we be transitioning from family-centred...looking after the interests of the family...to patient-centred care...putting the interests of the child first? Or are the two compatible? Do play and narrative therapy techniques mean that this transition can be made earlier, and is that desirable?

• I've been looking at play therapy and narrative therapy, both of which are paediatric psychotherapy techniques. It seems that some knowledge/adaptation of these techniques could help us to explore issues with young hearing-impaired children either using this tool or something else. Is this within the boundaries of our expertise? Or are we stepping into dangerous territory?

What do you feel might be the counselling needs of hearing impaired children? Who should be addressing those needs? Audiologists? Psychologists? Teacher of the Deaf? All? Others?

- Would you feel comfortable counselling hearing impaired children using a tool like this one in a rehabilitation session with a hearing-impaired child?
- Do you perceive a gap between the counselling by an Audiologist and a Psychologist? Do you think such a tool would be successful for bridging the gap between the roles of audiologists and psychologists? Why/why not?
- Do you feel you have a good understanding of hearing loss from the child's perspective? Or do you feel this is a 'gap' is helping hearing impaired children?

Would you feel comfortable counselling hearing impaired children as a role in their rehabilitation as a psychologist?

- Do you have extensive knowledge of Erik Erikson's stages of psychosocial development and Jean Piaget's theory of intellectual and perceptual development and how these relate to the psychosocial features of hearing-impaired children? Do you think these are important to using this tool?
- Do you feel there needs to be an alternative method for the counselling of hearing impaired children or do you feel current methods are effective? Are there issues that are not addressed with current clinical methods? Why/Why not? How/How not? Do you think these current methods could be combined with the 'My World' tool?
- Have you had any extra training in audiology/teaching?

The 'My World' tool itself Questions

- Do you think knowledge of psychology counselling skills (e.g. narrative or play therapy) and Erikson/Piaget theory would be useful in using this tool clinically for other professionals?
- Do you think there is a use for the Ida 'My World' tool <u>in psychology sessions</u> with hearing-impaired children? What is your view on such a tool? Do you think it is necessary and helpful?
- Would scenarios on how to use the tool to obtain certain information (e.g. questions on the summary sheet) be useful?
- Do you think it is clear on how to use the tool as it is currently presented?
- Do you think the tool needs more development? How about the tool items? Are they adequate in number and form?
- What age do you think is the most appropriate for the 'My World' tool? That is, what age of child will respond well to this tool/to assist hearing impaired children in different psychosocial stages of development? A particular age or range of age? should the packaging be different for different age groups?
- What is your opinion on the suggestions for use at different psychosocial stages of development? (show the page to interviewee as prompt)? What about the suggestion of the functional skills screening tool?
- Who do you think the tool should be used by? Audiologists? Psychologists? Teacher of the Deaf? All? Others?
- What do you think the tool should be used for <u>by Audiologists</u>? e.g. screening and referral, counselling on hearing strategies/social-emotional wellbeing, both, others?
- What do you think the tool should be used for <u>by psychologists</u>?
- When and what circumstances should the 'My World' tool be used?
- What is your opinion on the documentation form? Is it too vague?

- Do you have any comment on the supporting documents?
- Would you use the tool clinically as it is currently presented? Why/why not? (e.g. appointment time constraints, no clear instruction on how to use it clinically, current clinical methods in obtaining this information is effective.

Do you think there is a use for the Ida 'My World' tool in psychology sessions with hearing-impaired children? Do you think it is necessary and helpful? What issues do you see with it being used clinically (either psychologists/TOD/Audiologist)?

- Do you think parents could have a role in the use of this tool? e.g. Filial therapy? Why/why not?
- Do you think this tool could this enhance/improve the outcomes of paediatric rehabilitation?
- Do you think such a tool would be successful for bridging the gap between the roles of audiologists and psychologists? Why/why not?

What kind of uses in rehabilitation/therapy could this tool be useful for in psychology? What other uses do you potentially see for this tool in rehabilitation? Specific uses in psychology/Audiology, etc?

- Would this tool be useful for obtaining both the child's perspective of their hearing loss and helping the child? How can it be framed so that it is more intuitive for a Paediatric Audiologist or another professional to use?
- Do you see any other uses for this tool by other professionals? Do you see different ways this tool could be used clinically as a psychologist?

What additional skills or resources do you feel could enhance this role in the rehabilitation of hearing impaired children?

• What questions do you think can potentially be addressed by using the tool? If you can think of any further questions in addition to those on the summary form please describe? How could the tool be adapted to show how Audiologists/Professionals how to obtain such information in a clinical session?

APPENDIX (G) – 7-8 YEAR OLD INTERVIEWS SUMMARY FOR PARENTS

The Need and Uses of the Ida 'My World' Counselling Tool in Paediatric Rehabilitation for Hearing-impaired Children

Help us to communicate with young hearing-impaired children

Information for Parents of 7-8 year old Participants



- 1. Please read the following information in this summary. It will introduce you to the paediatric tool called 'My World' that could be used by Audiologists or other professionals such as a Teacher of the Deaf or Psychologist during a session with a hearing-impaired child. It will also detail the need to interview young children in this research project and the interview protocol.
- 2. After reading this summary, you are welcome to watch some videos on the tool if you wish. This will explain the tool to you and show you real life examples of the tool being used in an audiology session. There is a history for each of the children who are in the videos 2-4 supplied at the end of this summary.

Please watch the videos in the following order:

'My World' Instructional Video by Ida Institute
 Tool in Use – MyWorld_Emily_Classroom
 Tool in Use – MyWorld_Ashlynn_Outside
 Tool in Use – MyWorld_Chloe_Home

Please contact the researcher for the online access details to view these videos - this may be in the email sent to you.

3. An interview/discussion with your son/daughter will take place at a time/place organised with the researcher. The discussion with your son/daughter will involve finding out if they feel adequately prepared to manage /live well with their hearing loss at home, school and with their friends, if they feel able to formulate strategies for dealing with difficult communication situations, and their own experience with audiology services (i.e. to find out what they feel they need from the service). I can show you the tool in person at the end of this session and you may give your own opinions and thoughts on the 'My World' tool then. This discussion should take no longer than 45 minutes.

Any questions or difficulties with the viewing of the videos please email: 20351824@student.uwa.edu.au

Thank you for your time and participation in this research project.

Jessica Round

Master of Clinical Audiology Student

University of Western Australia

Supervisor – Karen Parfitt & Dr Robert Patuzzi

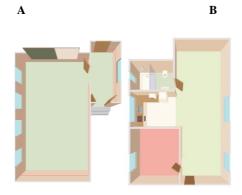
The Need and Uses of the Ida 'My World' Counselling Tool in Paediatric Rehabilitation for Hearingimpaired Children

Introduction: Because of their reduced vocabulary and communication skills, a child with a severe hearing loss can be at a great disadvantage in explaining to parents, teachers and professionals the problems they face day to day. The 'My World' tool, which is being developed at the Ida Institute, Denmark in collaboration with professionals from the US and the UK, is intended to be used during a consultation session to <u>support a dialogue about communication situations between a professional and a young child</u>. The tool is employing natural play, to enable a child to express actions, thoughts and concerns around communication situations in their lives, and providing the necessary physical objects to enable the child to problem solve and formulate logical solutions. Inherent in the development of this tool is motivational engagement, that is, making the child an active participant in his or her own rehabilitation program.

The tool depicts three different environments: a classroom, a home, and an outdoors area, as shown in Figure 1. The child can place moveable figures and everyday objects, as shown in Figure 2, in the various environments to describe their communication successes and challenges in their everyday life. Thus, the 'My World' tool can help facilitate an understanding of the child's hearing loss from his or her own point of view. By being curious and using open-ended questionning techniques, the professional can guide the child to talk about their communication and <u>develop a shared understanding about aspects of communication that are important to the child</u>. There is also a 'My World' listening guide, as shown in Figure 3, which can be for the professional to use to help them listen actively to what the child is saying.

The nine underlying principles in the tool prototype were:

- 1) Enable a patient-centred dialogue
- 2) Provide a supportive environment for children to tell their own experience
- 3) Joint focus and attention on what is relevant to the child
- 4) Discussion led by the family and child, related to their reality
- 5) Externalise issues related to hearing loss
- 6) Provide an insight into positive experiences and challenges faced by the child and family
- 7) Enable audiologists to hear details not usually obtained
- 8) Enable joint goal setting
- 9) Engaging and motivating





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Figure 1. The three different environmental boards of the Ida 'My World' tool, A: The classroom; B: The home; and C: the outdoors

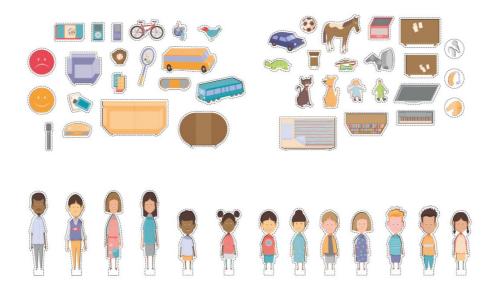


Figure 2. The moveable figures and everyday objects that the child can move around the different environment boards – the home, the classroom and the outdoors in the Ida 'My World' tool



Figure 3. The 'My World' tool listening guide, which can be used when actively listening to what the hearing-impaired child is saying

The Ida Institute have described a way in which to use the tool:

<u>Phase 1: Choosing the environment and being curious</u>. This is where the professional chooses the environment most relevant to the child in the appointment, and they ask the child to make it their own by selecting items that are meaningful to them in their daily life. The professional can ask open-ended questions and listen to the child's responses. This may begin by asking the child to give the professional a tour of the environment.

<u>Phase 2: Understanding successes and challenges and identifying strategies</u>. This is where, based on the descriptions given by the child, the professional can identify the child's current communication strategies. Those that work well may be reinforced by the professional, and those which the child describes as challenging, the professional can discuss with the child about possible new strategies which could result in more easy communication.

<u>Phase 3: Documenting decisions and strategies</u>. This phase is where the professional can use the documentation form, to record what was learned about the child's communication, and the goals and actions agreed upon.

What are the problems?

For the child

- Understanding that I am a person and not just a big blob of hearing loss
- Understanding that 'the hearing loss' is responsible for communication difficulties not me
- How do I fit in?...not by always insisting that I sit at the front of the class, and constantly telling the teacher to put the FM on, and by wearing hearing aids that draw attention to my differences.....
- I hate hearing tests, why do I have to go and no-one else does?
- I don't like having that Teacher of the Deaf/Notetaker following me around all the time, it looks like I'm a special needs kid...stigma
- Obtaining coping stratergies and emotional support/stratergies

For the professionals

- Gaining an accurate picture of the child's communication in real life
 - Information mostly obtained from parents or teachers. Do the parents/teachers really know about the all
 of a child's communication situations or might they have a different agenda?
 - Inter-agency communication channels not always free-flowing/efficient/effective
 - Timelyness of information
 - Accuracy of information
- Negotiating goals
- Often in family-centred care there is a danger that goals are the parent's or teachers' goals
- Goals focus on academic success and speech and language levels or hearing the 'sss'
- What is important to the child?
- Is there adequate attention to the well-being of the child?
- Evaluating intervention to date
- Based on teacher/parental report? Do we ask the child?
- Parents and teachers report on academic success. Does this provide sufficient evidence of successful rehabilitation?
- How do we find the effectiveness of intervention in providing good quality of life and well-being to the child?
- Planning future intervention that addresses things that really matter to the child
 - Based on goals, do they reflect the real-life needs of the child?
 - Are the interventions specific to the child's needs?
- 'Compliance' with rehabilitation
 - Should we be looking for concordance...where the child and the audiologist make decisions together?
 Would engaging the child to take charge of their own communication needs increase concordance as is the case in adult rehabilitation?
- Looking beyond amplification
 - How do we help children to employ effective strategies to use their amplification to communicate effectively?
 - How do we formulate intervention that a child believes that they can implement?

It is important to acknowledge that there may be confusion of the roles/processes of the tool in the clinical setting from which the Ida Institute developed the tool, and that the tool may need further refinement. Defined uses for this tool are yet to be established and are a goal of this project to ascertain.

Tool in Use - MyWorld Emily_Classroom

- Emily is a 7-year-old girl with Treacher Collins Syndrome. Emily's has a bilateral conductive hearing loss and uses an implanted bone conduction device on one ear and a hearing aid on the other ear.
- Emily's audiologic care was complicated due to a significant phobia for medical services that developed around 2 years of age. Using the 'My World' tool at visits when she was 5 and 6 years of age has allowed Emily to share her perspectives through imaginative play.
- Emily's audiologist has used the tool twice with her, exploring communication in the home setting and to teach her more about Emily's communication partners at school.
- Emily's Audiologist has been able to use the information gained through both sessions to develop strategies in terms of behaviour changes and using technology to enhance Emily's communication skills in different settings.

Tool in Use - MyWorld_Ashlynn_Outside

- Ashlynn was 9 years old when she was filmed using the 'My World' Tool. She has a bilateral, moderately-severe, sensorineural hearing loss that was not diagnosed until she was 4 years of age.
- Her hearing care professional used the 'My World' tool to facilitate a discussion of her relationship with her younger sister. Her younger sister was diagnosed with hearing loss and there was a need to explore their relationship and how Ashlynn could support her sister's use of technology.
- Through their discussion, Ashlynn's Audiologist learned a lot about how Ashlynn handles relationships. This has opened up the opportunity for them to explore how her impaired communication skills impact her relationships. It also allowed her to discuss how Ashlynn can support her sister and family in using more effective communication strategies.

Tool in Use - MyWorld_Chloe_Home

- Chloe has been using hearing aids effectively for the last five years. She has regular contact with her Teacher of the Deaf in school and is a 'model' hearing aid and FM user.
- As she is managing so well at school, Chloe's hearing care professional, Richard, decided to explore her home environment using the 'My World' tool. In the past, Chloe has been fairly shy in the clinic and has not expressed any difficulty at home or in social situations.
- The session with the tool not only revealed the difficulties she experiences with communication at home, but also enabled Chloe's parents to realize how many situations, which are often taken for granted, pose real communication difficulties for her.
- Richard feels that the session helped Chloe's parents gain a better understanding of her difficulties but also aided him in being able to tailor her hearing aid management and counselling appropriately.

What questions can potentially be addressed using the tool: (This is not a definitive list)

Audiologist	Psychologist	Teacher of the Deaf
•What are the child's most difficult listening situations? Where are they? Home, school, etc?	•Does the child have good self-esteem?	•How well does the child communicate with their peers?
•Who does the child have trouble communicating with/understanding?	•Does the child have a good self concept?	 What are the main situations where the child has difficulties hearing in the classroom?
•Is the child using their FM successfully in class? Is it helping them?	•Does the child have good self efficacy?	•How effective does the child find their FM system in the classroom?
•How does the child manage with their hearing loss at home?	•How does the child self perceive?	•What are the child's most difficult listening situations? Where are they? Home, school, etc?
• What are the child's communication successes and challenges?	•What are the child's attitudes towards self/others?	•How well does the child communicate with their classroom teacher/s?
•What are the child's limitations with their current amplification?	•What are the child's attitudes towards hearing impairment?	•What are the child's attitudes towards self/others?
•How does the child go about self advocacy? How do they feel about doing this?	•What are the child's attitudes towards their hearing aids/CIs, etc?	•What are the child's positive and negative experiences with having a hearing loss?
•What strategies can help the child in their communication challenges?	•Does the child receive emotional support from their family/friends?	•Does the child self advocate with about their hearing loss?
•How does the child perceive their current amplification (i.e. is it adequate)?	•What are the child's behavioural issues in particular situations?	•How does the child feel others perceive them?
•How does the child manage with their hearing loss with peers?	•What are the child's positive and negative experiences with having a hearing loss?	•Are the current classroom strategies helping the child from their view?
•How does the child perceive their hearing loss?	•What is the psychosocial developmental level of the child?	•What is the child's level of spoken English?
• Find out if child is actually using the amplification, where and when	•What is the child's level of self-reliance?	•Does the child have adequate access to the school curriculum?
• Identify situations where is the child communicating successfully?	•Does the child have a good level of environmental awareness?	•How does the child perceive help from their educational assistant/ interpreter?
 Deconstructing with a child the communication strategies that he or she is already employing successfully 	•Does the child have anxiety in specific situations?	•
Identify communication challenges that are important to the child	•Does the child have an emotional disorder? (e.g. anger/frustration/impulsivity)	
• Are there strategies that the child is already employing successfully in one situation that might help in another?	•Does the child have behavioural control?	
 Uncover any maladaptive strategies that need to be addressed? 	 How does the child behave non-verbally? 	
 Help the child to 're-story' his or her perspective to highlight strengths and successful strategies 		
• Externalise the hearing loss		
 Co-formulate strategic solutions to communication challenges that are practicable 		
 Explore self-efficacy issues that may hinder successful employment of communication strategies 		
Rehearse self-advocating vocabulary to use in real-life communication situations specific to the child		
 Problem –solve new strategies for communication situations that are not working and causing unhappiness 		
 Engage the child in his or her own rehabilitation program 		
Evaluation of intervention to date		
 Negotiation of goals to be addressed by future intervention 		
Planning of future intervention		

The reasons for interviewing children in this project:

The main aim of this project is to find out if there is a need for the 'My World' tool and to document and develop more specific uses for the tool. The project is also investigating if the tool could be used by other professionals such as Teachers of the Deaf/Visiting Teachers and Psychologists. It is important to find out if there is a need from *both* the professionals and the clients (children) to be able to document a more holistic picture of its need and highlight specific areas of what it could be used for clinically. Thus it is necessary to find out whether hearing-impaired children feel adequately prepared to manage /live well with their hearing loss at home, school and with their friends and their experiences with professionals from the hearing-impaired children need from the service. It will also be useful to find out whether they think that 'play 'scenarios (i.e. externalisation of the hearing loss) would be a good idea to act out a communication situation with an Audiologist and their opinions on the tool's content (e.g. the items). It is hoped that the children interviewed will be able to reflect on intervention services for hearing-impaired children and benefit by being able to express where help is needed, in safe neutral setting outside of a clinic. Thus, it is hoped that this study can contribute to providing a more holistic rehabilitation program to hearing-impaired children and their families.

The protocol for the interview:

As we are trying to obtain the child's perspective it will be necessary for the child to be interviewed with you listening and/or observing outside if possible, or with you next to the child without prompts from you. This is because your child may tend to look to you/ask you for direction for their response, and it is best for there to be no prompting from the parent. This allows the researcher to obtain unbiased responses from the child alone. At the end of the discussion with your child, I will invite you to share your thoughts and opinions on the 'My World' tool. The interview will be recorded with your permission as per the information form.

Thank you for your time and participation in this research project.

APPENDIX (H) – INTERVIEW FORMAT FOR 7-8 YEAR OLDS

Interview questions/format for hearing-impaired 7-8 year olds

1. Introduce myself

- Discuss who I am and my experience with hearing loss to both the parent and child. Let the parent know that I am trying to get the perspectives of their child, so it would be appreciated if they gave their child the opportunity to speak give a rundown of the interview format to reiterate this. Let them know their own feedback at the end is appreciated.
- Discuss what I am trying to get them to help me obtain with the project to the parent (i.e. to help young hearingimpaired children), and thank them for wanting to participate.

2. <u>Introductions with the child</u>

• Sit down with the child at their level and allow time to build a rapport with the child – talk about their hearing aids and show them mine (e.g. talk about colours of hearing aids if they have colours and talk about what colour mine used to be). Talk to them about their favourite game, etc.

3. Obtaining information: School

- Ask the child if there are situations that they have trouble hearing in at school.
- If the child finds this difficult offer some suggestions e.g. hearing the teacher when they read the class a story or at assembly, or when the class is noisy.
- Ask them what they do about that situation do they alert the teacher? Do they know what to do in this situation?
- Do you tell your teacher when you have trouble hearing?
- Do you get the teacher to use your FM system?
- Does your visiting teacher help you discuss ways to help you hear better in the classroom?
- Do you tell your friends when you can't hear in the playground?
- Do you know what your hearing aids can help you with at school? Do you know what you might have trouble hearing with your hearing aids at school?
- Do your friends help you when you can't hear?
- Do you tell the other people in your class about your hearing aids and that you can't hear so well?

4. Obtaining information: Social

- Ask the child if there are situations that they have trouble hearing when they are playing with their friends or when they are at the park or in the car or on the train/bus.
- If the child finds this difficult offer some suggestions e.g. In the car with the radio on, or hearing a friend talk to them from a distance in the park
- Ask them what they do about that situation do they know what to say to their friends? Do they know what to do in this situation?
- Do they tell people about their hearing loss?
- Do other kids include you in games?
- Do you ask people to help you understand when you can't hear what is being said?
- Do you feel left out sometimes?

5. Obtaining information: Home

- Do you tell your parents/brothers/sisters when you can't hear them?
- Do you ask them to help you understand when you can't hear?
- Are these situations at home you have trouble hearing in? (e.g. talking when the TV is on, or being called from another room?) What do you do so you can hear better?
- Can you understand what is being said at the dinner table or at family get-togethers? Do you know what to do so you can hear better?
- 6. Obtaining information: Audiology services
 - Does you audiologist (the lady/man who sets up your hearing aids) help you when you don't know what to do in situations you can't hear?
 - What would you like them to help you with? (i.e. knowing how to hear better in situations? e.g. strategies)
- 7. Bring out the 'My World' tool and show it to them. Ask the child some questions about the tool:
 - What do you think about this game to discuss how you hear in the classroom, at home and outdoor? Can you show me better where you have trouble than if you were just talking to me about where you have trouble hearing?
 - Are their more toys that need to be included? What about the people?
- 8. <u>Parent's perspective Invite the parent to give their own feedback on the videos they have watched and what they think about the tool.</u>
 - Ask the parent/s what they think of the tool? (Show it to them). Do they think it's a good idea? Would they like to use it themselves? What do they think of the videos?
- 9. Conclude the interview and thank the parent and child for participating

APPENDIX (I) – SUMMARY FOR TEENAGERS

Help us to communicate with young hearing-impaired children



My name is Jessica Round, and I am completing my Master of Clinical Audiology this year. I grew up hearingimpaired (I have a moderately severe-profound sensorineural hearing loss in my left ear and a mild steeply sloping to profound hearing loss in my right ear) and I wear two hearing aids. I am conducting a research project into a kit which could help hearing-impaired children communicate their needs to Audiologists and other professionals, and help in their ability to formulate strategies for dealing with difficult listening situations.

I am asking of your help as a teenager to give me your thoughts on this kit and offer your own experiences with professionals which will be used to help hearing-impaired children.

- 1. Please read these pages before I meet with you they will introduce you to the 'My World' kit.
- 2. At the meeting with you, I will show you some videos on the kit which will show you real life examples of the kit being used. I will explain the child's background for each example.
- 3. After watching the videos with me, I will show you what the kit looks like in person, and would like to discuss with you your opinions on the kit and the videos, whether you think it is a valuable kit which could be incorporated into sessions and how or if it needs to be improved, as well as your own experiences with audiology services. This discussion should take about an hour to an hour and a half.
 - 4. As a thank you for your time, a cinema movie voucher will be issued to you at the end of the discussion.

Any questions please email: 20351824@student.uwa.edu.au

Thank you for your time and participation in this research project.

Jessica Round

Master of Clinical Audiology Student

University of Western Australia

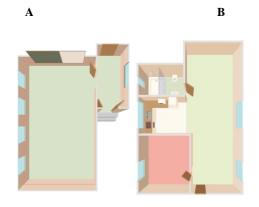
Supervisor – Karen Parfitt & Dr Robert Patuzzi

Introduction: We know that any child with a severe hearing loss can be at a great disadvantage in explaining to parents, teachers and professionals the problems they face day to day. We hope that the 'My World' kit¹ which can be used in a hearing session will help the child to <u>communicate their world to a professional</u>. The kit uses natural play, to enable a child to express actions, thoughts and concerns around communication situations in their lives. This will help with <u>making the child an active participant in his or her own rehabilitation program</u>.

The kit shows three different environments: a classroom, a home, and an outdoors area, as shown in picture 1. The child can place the cutouts, as shown in picture 2, in the environments to describe the world around them. The 'My World' kit can help facilitate an understanding of the child's hearing loss from his or her own point of view. By being curious and using questions, the professional can guide the child to talk about their communication and <u>develop a shared understanding about aspects of communication that are important to</u> <u>the child</u>. There is also a 'My World' listening guide, as shown in picture 3, which can be for the professional to use to help them listen actively to what the child is saying.

The nine underlying principles in the kit design were:

- 1) Enable patient-centred communication
- 2) Provide a supportive environment for children to tell their own experience
- 3) Focus and attention on what is relevant to the child
- 4) Discussion led by the family and child, related to the child's experience
- 5) Externalise issues related to hearing loss
- 6) To show an insight into positive experiences and challenges faced by the child and family
- 7) Enable audiologists to hear details not usually obtained
- 8) Enable joint goal setting
- 9) Engaging and motivating

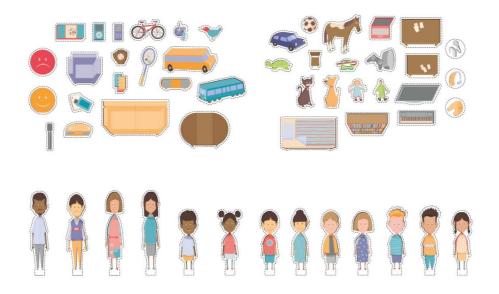


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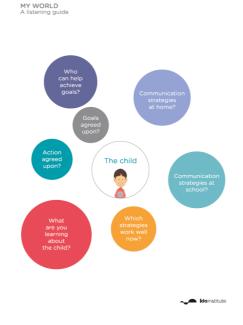


Picture 1. The three different environmental boards of the Ida 'My World' kit, A: The classroom; B: The home; and C: the outdoors

¹ The 'My World' kit was developed by the Ida Institute in Denmark in collaboration with Audiologists from the UK and US.



Picture 2. The moveable figures and everyday objects that the child can move around the different environment boards – the home, the classroom and the outdoors in the Ida 'My World' kit



Picture 3. The 'My World' kit listening guide, which can be used when actively listening to what the hearing-impaired child is saying

The Ida Institute have described a way in which to use the kit:

<u>Phase 1: Choosing the environment and being curious</u>. This is where the professional chooses the environment most relevant to the child in the appointment, and they ask the child to make it their own by selecting items that are meaningful to them in their daily life. The professional can ask questions and listen to the child's responses. This may begin by asking the child to give the professional a tour of the environment.

<u>Phase 2: Understanding successes and challenges and identifying strategies</u>. This is where, based on the descriptions given by the child, the professional can identify the child's current communication strategies. Those that work well may be reinforced by the professional, and those which the child describes as challenging, the professional can discuss with the child about possible new strategies which could result in more easy communication.

<u>Phase 3: Documenting decisions and strategies</u>. This phase is where the professional can use the documentation form, to record what was learned about the child's communication, and the goals and actions agreed upon.

What are the problems?

For the child

- Understanding that I am a person and not just a big blob of hearing loss
- Understanding that 'the hearing loss' is responsible for communication difficulties not me
- How do I fit in?...not by always insisting that I sit at the front of the class, and constantly telling the teacher to put the FM on, and by wearing hearing aids that draw attention to my differences.....
- I hate hearing tests, why do I have to go and no-one else does?
- I don't like having that Teacher of the Deaf/Notetaker following me around all the time, it looks like I'm a special needs kid...stigma
- Obtaining coping stratergies and emotional support/stratergies

For the professionals

- Gaining an accurate picture of the child's communication in real life
 - Information mostly obtained from parents or teachers. Do the parents/teachers really know about the all
 of a child's communication situations
 - Inter-agency (e.g. WAIDE/Australian Hearing/Telethon Speech and Hearing) communication channels not always free-flowing/efficient/effective
 - Time and accuracy of information
- Negotiating goals
- There is a danger that goals are the parent's or teachers' goals and not the child's goals
- Goals focus on academic success and speech and language levels or hearing the 'sss'
- What is important to the child?
- Is there adequate attention to the well-being of the child?
- Evaluating supprt services to date

 Based on teacher/parental report? Do we ask the child?
 Parents and teachers report on academic success. Does this provide sufficient evidence?

 Planning future support services that addresses things that really matter to the child
 - Based on goals, do they reflect the real-life needs of the child?
 - Are the services specific to the child's needs?
- 'Compliance' with rehabilitation
 - Should we be looking for where the child and the audiologist make decisions together?
 - Would engaging the child to take charge of their own communication needs increase compliance? Looking beyond amplification (e.g. hearing aids, cochlear implants, etc)
 - How do we help children to employ effective strategies to use their amplification to communicate effectively?

It is important to acknowledge that there may be confusion of the roles/processes of the kit in the clinical setting from which the Ida Institute developed the kit, and that the kit may need further refinement. Defined uses for this kit are yet to be established and are a goal of this project to ascertain.

The next page lists some questions that could possibly be addressed by using the 'My World' kit.

Thank you for your time and participation in this research project.

What questions can potentially be addressed using the kit: (This is not a defined list)

Audiologist	Psychologist	Teacher of the Deaf
_		
•What are the child's most difficult listening situations? Where are they? Home, school, etc?	•Does the child have good self-esteem?	•How well does the child communicate with their peers?
•Who does the child have trouble communicating with/understanding?	•Does the child have a good self concept?	•What are the main situations where the child has difficulties hearing in the classroom?
•Is the child using their FM successfully in class? Is it helping them?	•Does the child have good self efficacy?	•How effective does the child find their FM system in the classroom?
•How does the child manage with their hearing loss at home?	•How does the child self perceive?	•What are the child's most difficult listening situations? Where are they? Home, school, etc?
•What are the child's communication successes and challenges?	•What are the child's attitudes towards self/others?	•How well does the child communicate with their classroom teacher/s?
•What are the child's limitations with their current amplification?	•What are the child's attitudes towards hearing impairment?	•What are the child's attitudes towards self/others?
•How does the child go about self advocacy? How do they feel about doing this?	•What are the child's attitudes towards their hearing aids/CIs, etc?	•What are the child's positive and negative experiences with having a hearing loss?
•What strategies can help the child in their communication challenges?	•Does the child receive emotional support from their family/friends?	•Does the child self advocate with about their hearing loss?
•How does the child perceive their current amplification (i.e. is it adequate)?	•What are the child's behavioural issues in particular situations?	•How does the child feel others perceive them?
•How does the child manage with their hearing loss with peers?	•What are the child's positive and negative experiences with having a hearing loss?	from their view?
•How does the child perceive their hearing loss?	•What is the psychosocial developmental level of the child?	•What is the child's level of spoken English?
• Find out if child is actually using the amplification, where and when	•What is the child's level of self-reliance?	•Does the child have adequate access to the school curriculum?
Identify situations where is the child communicating successfully?	•Does the child have a good level of environmental awareness?	•How does the child perceive help from their educational assistant/ interpreter?
• Deconstructing with a child the communication strategies that he or she is already using successfully	•Does the child have anxiety in specific situations?	•
Identify communication challenges that are important to the child	•Does the child have an emotional disorder? (e.g. anger/frustration/impulsivity)	
 Are there strategies that the child is already employing successfully in one situation that might help in another? 	•Does the child have behavioural control?	
• Uncover any maladaptive strategies that need to be addressed?	•How does the child behave non-verbally?	
 Help the child to 're-story' his or her perspective to highlight strengths and successful strategies 		
• Externalise the hearing loss		
 Co-formulate strategic solutions to communication challenges that are practicable 		
 Explore self-efficacy issues that may hinder successful employment of communication strategies 		
Rehearse self-advocating vocabulary to use in real-life communication situations specific to the child		
 Problem –solve new strategies for communication situations that are not working and causing unhappiness 		
Engage the child in his or her own rehabilitation program		
Evaluation of intervention to date		
 Negotiation of goals to be addressed by future intervention 		
 Planning of future support services 		

APPENDIX (J) – INTERVIEW FORMAT FOR TEENAGERS

Interview questions/format for hearing-impaired 14-15 year olds

1. <u>Introduce myself</u>

- Discuss who I am and my experience with hearing loss and talk about their hearing loss/hearing aids.
- Discuss what I am trying to get them to help me obtain with the project i.e. to help young hearing-impaired children.
- Thank them for wanting to participate.
- Mention that they will get a movie voucher at the end of the session today.

2. Show the teen the 'My World' tool and ask the following questions:

- What is your first reaction to the tool?
- Do you think the tool needs more development? How about the tool items such as the figures? Are they adequate in number and form? What would you like to see included/changed with this tool?
- What age do you think is the most appropriate for the 'My World' tool?
- Should the packaging be different for different age groups? What kind of packaging?
- Who do you think the tool should be used by? Audiologists? Psychologists? Teacher of the Deaf? All? Others?
- What do you think the tool should be used for? (e.g. helping with hearing strategies)
- Can you think of specific situations it could be used for?
- When should the 'My World' tool be used? (e.g. annual review appointments, hearing aid reviews, etc.?)
- Do you think the tool could be used as it is currently presented? Why/why not?
- Do you think there is a need for this tool?
- Do you think this tool would have been helpful when you were young to express your perspective of your hearing loss to Audiologists and Teachers of the Deaf, etc.?
- Do you see any other uses for this tool or different ways this tool could be used?

3. <u>Show teen the Introduction video:</u>

• What do you think of the intro video?

4. Show the teen the Kathleen and her family video:

• Was the Kathleen and her family video very relevant and does it highlight a need for this tool? Can you relate to the video?

5. <u>Show the teen the 3 videos of the tool in use:</u>

- What do you think about the three videos of the tool being used?
- Is there anything the Audiologists could have done better?
- Do you think this tool helped the child express their perspective of their hearing loss well and for the Audiologist to get some info about this?
- What do you think would help for Audiologists who would use this tool?
- Do you have any other comments on the videos?

6. <u>Discuss the teens own experience with their hearing loss and audiology services. Firstly ask a few questions and then go through with them (help them with examples if they get confused about a question) and get them to fill in the tables attached.</u>

- Do you think your Audiologist when you were in primary school had a good understanding of your perspective of your hearing loss? What about your Teacher of the Deaf?
- How could we improve in helping young children to help themselves in difficult communication environments (self-advocate)?
- Are their issues that are not addressed in audiology sessions or sessions with Teachers of the Deaf? How could these be looked at?
- What other things would be helpful in audiology sessions?
- 7. <u>Wrap up the session by thanking the teen for their participation and give them the movie voucher.</u>

Please rate the following aspects of your own experience with school, social and home life <u>AS A</u> <u>CHILD in Primary School (PLEASE TICK THE BOXES):</u>

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD AT SCHOOL					
I was prepared for discussing hearing issues/difficulties with my teachers					
I was prepared for discussing my hearing issues with my peers					
I felt able to self-advocate (for example: asking for help when you can't hear and use of FM) at school					
I readily self-advocated in class					
I readily self-advocated in the playground					
I needed strategies for how to cope in the classroom					
My Visiting Teacher of the Deaf/Teacher of the Deaf adequately helped me when I had difficulties in school					
I was not confident and was a shy child in class					
I used communication strategies at school to help me					
I knew how to adequately discuss things such as notetakers, education assistants and FMs to other students and teachers					
I had a full understanding of the benefits and limitations of hearing aids at school					
I felt peers were willing to help me when I needed assistance					
I felt accepted by students at my school					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD AT HOME					
I adequately discussed my hearing difficulties with my parents					
I adequately discussed my hearing difficulties with my siblings					
I was encouraged by my family to self-advocate					
I felt able to self-advocate at home					
I used communication strategies at home to help me					
I had a full understanding of the benefits and limitations of amplification around the home					
I felt included in the things my family did together as a child					
I felt left out of family conversations					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
AS A CHILD DURING SOCIAL ACTIVITIES					
I felt left out as a child					
I felt okay explaining to others that I am deaf or hard-of-hearing					
My self-esteem was excellent as a child					
I found self-advocating for inclusiveness difficult					
I was adequately prepared for communication strategies in social situations					
I tended to not discuss my hearing loss or difficulties with other children					
I felt able to self-advocate in social situations					
I used communication strategies in social situations to help me					
I had a full understanding of the benefits and limitations of amplification in social situations					
I felt okay asking for what I wanted at public places e.g. shop assistants, etc.					
I felt embarrassed asking people to repeat themselves					
As a hearing-impaired child it was easy for me to start talking to people I didn't know					
I felt I missed out on activities and things I wanted to do					

APPENDIX (K) – 20-26 YEAR OLD SUMMARY

The Need and Uses of the Ida 'My World' Counselling Tool in Paediatric Rehabilitation for Hearing-impaired Children

Jessica Round, Master of Clinical Audiology, Supervisor – Karen Parfitt & Dr Robert Patuzzi

Introduction: Because of their reduced vocabulary and communication skills, a child with a severe hearing loss can be at a great disadvantage in explaining to parents, teachers and professionals the problems they face day to day. The 'My World' tool, which is being developed at the Ida Institute, Denmark in collaboration with professionals from the US and the UK, is intended to be used during a consultation session to support a dialogue about communication situations between a professional and a young child. The tool is employing natural play, to enable a child to express actions, thoughts and concerns around communication situations in their lives, and providing the necessary physical objects to enable the child to problem solve and formulate logical solutions.

Research-based best practice in audiology is currently family-centred in paediatric rehabilitation, and patient-centred in adult rehabilitation. At what age should rehabilitation transition from one to the other? Inherent in the development of this tool is the assumption that motivational engagement is as critical to successful paediatric rehabilitation as it is to successful adult rehabilitation, and that making the child an active participant in his or her own rehabilitation program as early as possible will yield comparable benefits.

The tool depicts three different environments: a classroom, a home, and an outdoors area. The child can place moveable figures and everyday objects in the various environments to describe their communication successes and challenges in their everyday life. Thus, the 'My World' tool can help facilitate an understanding of the child's hearing loss from his or her own point of view. By being curious and using open-ended questionning techniques, the professional can guide the child to talk about their communication and develop a shared understanding about aspects of communication that are important to the child.

What are the problems?

For the professionals

• Gaining an accurate picture of the child's communication in real life

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- Information mostly obtained from parents or teachers. Do the parents/teachers really know about the all of a child's communication situations or might they have a different agenda?
 - Inter-agency communication channels not always free-flowing/efficient/effective
- Timelyness of information
- Accuracy of information
- Negotiating goals
- Often in family-centred care there is a danger that goals are the parent's or teachers' goals
- Goals focus on academic success and speech and language levels or hearing the 'sss'
- What is important to the child?
- Is there adequate attention to the quality of life and well-being of the child?
- Evaluating intervention to date
- Based on teacher/parental report? Do we ask the child?
- Parents and teachers report on academic success. Does this provide sufficient evidence of successful rehabilitation?
- How do we find the effectiveness of intervention in providing good quality of life and well-being to the child?
- Planning future intervention that addresses things that really matter to the child
 - Based on goals, do they reflect the real-life needs of the child?
 - Are the interventions specific to the child's needs. For example, are we fitting an FM system 'because it increases the signal to noise' or as an integral part of achieving a communication goal that will improve the child's quality of life?
- 'Compliance' with rehabilitation
 - Compliance suggests submission, should we be looking for concordance...where the child and the audiologist make decisions together?
 - Would engaging the child to take charge of their own communication needs increase concordance as is the case in adult rehabilitation?
- Looking beyond amplification
- How do we help children to employ effective strategies to use their amplification to communicate effectively? For example, a printed list starting with sit at the front of the class...how much will this impact on a child's communication?
- Self-efficacy...how do we formulate intervention that a child believes that they can implement?

For the child

- Understanding that I am a person and not just a big blob of hearing loss
- Understanding that 'the hearing loss' is responsible for communication difficulties not me
- How do I fit in?...not by always insisting that I sit at the front of the class, and constantly telling the teacher to put the FM on, and by wearing hearing aids that draw attention to my differences.....
- I hate hearing tests, why do I have to go and no-one else does?
- I don't like having that Teacher of the Deaf/Notetaker following me around all the time, it looks like I'm a special needs kid...stigma
- Obtaining coping stratergies and emotional support/stratergies

The nine underlying principles in the tool prototype were:

- 1) Enable a patient-centred dialogue
- 2) Provide a supportive environment for children to tell their own experience
- 3) Joint focus and attention on what is relevant to the child
- 4) Discussion led by the family and child, related to their reality
- 5) Externalise issues related to hearing loss
- 6) Provide an insight into positive experiences and challenges faced by the child and family
- 7) Enable audiologists to hear details not usually obtained
- 8) Enable joint goal setting
- 9) Engaging and motivating

It is important to acknowledge that there may be confusion of the roles/processes of the tool in the clinical setting from which the Ida Institute developed the tool, and that the tool may need further refinement. Defined uses for this tool are yet to be established and are a goal of this project to ascertain.

<u>What questions can potentially be addressed using the tool:</u> (This is not a definitive list, and please feel free to comment on your own in the questionnaire).

•What are the child's most difficult listening situations? Where are they? Home, school, etc?	•Does the child have good self-esteem?	
they? nome, school, etc?	• Does the child have good sen-esteem?	•How well does the child communicate with their peers?
•Who does the child have trouble communicating with/understanding?	•Does the child have a good self concept?	•What are the main situations where the child has difficulties hearing in the classroom?
•Is the child using their FM successfully in class? Is it helping them?	•Does the child have good self efficacy?	•How effective does the child find their FM system in the classroom?
•How does the child manage with their hearing loss at home?	•How does the child self perceive?	•What are the child's most difficult listening situations? Where are they? Home, school, etc?
•What are the child's communication successes and challenges?	•What are the child's attitudes towards self/others?	•How well does the child communicate with their classroom teacher/s?
•What are the child's limitations with their current amplification?	•What are the child's attitudes towards hearing impairment?	•What are the child's attitudes towards self/others?
•How does the child go about self advocacy? How do they feel about doing this?	•What are the child's attitudes towards their hearing aids/CIs, etc?	•What are the child's positive and negative experiences with having a hearing loss?
•What strategies can help the child in their communication challenges?	•Does the child receive emotional support from their family/friends?	•Does the child self advocate with about their hearing loss?
 How does the child perceive their current amplification (i.e. is it adequate)? 	•What are the child's behavioural issues in particular situations?	•How does the child feel others perceive them?
•How does the child manage with their hearing loss with peers?	•What are the child's positive and negative experiences with having a hearing loss?	•Are the current classroom strategies helping the child from their view?
•How does the child perceive their hearing loss?	•What is the psychosocial developmental level of the child?	•What is the child's level of spoken English?
Find out if child is actually using the amplification, where and when	•What is the child's level of self-reliance?	•Does the child have adequate access to the school curriculum?
Identify situations where is the child communicating successfully?	•Does the child have a good level of environmental awareness?	 How does the child perceive help from their educational assistant/ interpreter?
Deconstructing with a child the communication strategies that he or she is already employing successfully	•Does the child have anxiety in specific situations?	
Identify communication challenges that are important to the child	•Does the child have an emotional disorder? (e.g. anger/frustration/impulsivity)	
Are there strategies that the child is already employing successfully in one situation that might help in another?	•Does the child have behavioural control?	
Uncover any maladaptive strategies that need to be addressed?	•How does the child behave non-verbally?	
Help the child to 're-story' his or her perspective to highlight strengths and successful strategies		
Externalise the hearing loss		
Co-formulate strategic solutions to communication challenges that are practicable		
Explore self-efficacy issues that may hinder successful employment of communication strategies		
Rehearse self-advocating vocabulary to use in real-life communication situations specific to the child		
Problem -solve new strategies for communication situations that are not working and causing unhappiness		
Engage the child in his or her own rehabilitation program	1	1
Evaluation of intervention to date		1
Negotiation of goals to be addressed by future intervention		1
Planning of future intervention	1	1

After reading the introduction above and in considering the questions that the tool could be used to address, please firstly look at the tool components:

- 1. MyWorld_Intro_Sheet
- 2. MyWorld_listening_guide
- 3. MyWorld_Documentation_form
- 4. MyWorld_Boards
- 5. MyWorld_All_Items

And then watch the videos of the tool in use in the following order:

- 1. 'My World' Instructional Video by Ida
- 2. Kathleen and her family Video
- 3. Tool in Use MyWorld_Emily_Classroom
- 4. Tool in Use MyWorld_Ashlynn_Outside
- 5. Tool in Use MyWorld_Chloe_Home

It is important to note that these videos do not demonstrate perfect use of how to use the 'My World' tool, and some may be quite poor examples.

To access the tool components and the videos:

Please go to Google, click on Drive (top left corner), and login using the below address and password. They are located in the My Drive folder.

Address: myworldresearchprojectuwa@gmail.com

Password:

Please note that it is a condition of your participation in this project that downloading, saving or distribution of the videos is not consented.

Any questions or difficulties with the viewing of the videos or any of the material please email: 20351824@student.uwa.edu.au

Below is a brief case history for each of the tool in use and the Kathleen and her family videos:

Kathleen and her family

- It appears Kathleen's parents had a difficult time understanding and coming to grips with Kathleen's hearing loss. Kathleen experienced bouts of depression and loneliness during her youth, but Kathleen's parents remained frozen. The family did not openly discuss Kathleen's situation or take concrete action to reach out to Kathleen and assess how she was dealing with her hearing loss.
- This story highlights the enormous value of encouraging families to openly discuss hearing loss and creating a space for that discussion to occur. The consequences of hearing loss can be described in terms of decibels and frequencies, but also in terms of social and emotional aftershocks. While it is not possible to address all issues related to hearing loss, it is important that one remembers to treat the whole patient, the whole family, and not just the hearing loss itself.

Tool in Use - MyWorld_Emily_Classroom

- Emily is a 7-year-old girl with Treacher Collins Syndrome. Emily's has a bilateral conductive hearing loss and uses an implanted bone conduction device on one ear and a hearing aid on the other ear.
- Emily's audiologic care was complicated due to a significant phobia for medical services that developed around 2 years of age. Using the 'My World' tool at visits when she was 5 and 6 years of age has allowed Emily to share her perspectives through imaginative play.
- Emily's audiologist has used the tool twice with her, exploring communication in the home setting and to teach her more about Emily's communication partners at school.
- Emily's Audiologist has been able to use the information gained through both sessions to develop strategies in terms of behaviour changes and using technology to enhance Emily's communication skills in different settings.

Tool in Use - MyWorld Ashlynn Outside

- Ashlynn was 9 years old when she was filmed using the 'My World' Tool. She has a bilateral, moderately-severe, sensorineural hearing loss that was not diagnosed until she was 4 years of age.
- Her hearing care professional used the 'My World' tool to facilitate a discussion of her relationship with her younger sister. Her younger sister was diagnosed with hearing loss and there was a need to explore their relationship and how Ashlynn could support her sister's use of technology.
- Through their discussion, Ashlynn's Audiologist learned a lot about how Ashlynn handles relationships. This has opened up the opportunity for them to explore how her impaired communication skills impact her relationships. It also allowed her to discuss how Ashlynn can support her sister and family in using more effective communication strategies.

Tool in Use - MyWorld_Chloe_Home

- Chloe has been using hearing aids effectively for the last five years. She has regular contact with her Teacher of the Deaf in school and is a 'model' hearing aid and FM user.
- As she is managing so well at school, Chloe's hearing care professional, Richard, decided to explore her home environment using the 'My World' tool. In the past, Chloe has been fairly shy in the clinic and has not expressed any difficulty at home or in social situations.
- The session with the tool not only revealed the difficulties she experiences with communication at home, but also enabled Chloe's parents to realize how many situations, which are often taken for granted, pose real communication difficulties for her.
- Richard feels that the session helped Chloe's parents gain a better understanding of her difficulties but also aided him in being able to tailor her hearing aid management and counselling appropriately.

Following the viewing of the videos please fill out the accompanying questionnaire, and scan and email it to:

20351824@student.uwa.edu.au

Thank you for your time and participation in this research project.

Jessica Round

Master of Clinical Audiology Student

University of Western Australia

APPENDIX (L) – 20-26 YEAR OLD QUESTIONNAIRE

Hearing-impaired 20-26 year old Questionnaire

The Ida 'My World' Counselling Kit in Paediatric Rehabilitation for Hearing-impaired Children

1. What was your first reaction to the kit?

Click here to enter text.

2. Please rate the following aspects of the videos (please click the box you agree with – select only one):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The instructional video was informative					
The instructional video needs to be more informative for the Audiologist (i.e. give detailed scenarios for the kit's use)					
The "Kathleen and her family" video was very relevant and highlights the need for the My World kit					
I could relate to aspects of the "Kathleen and her family" video					
Use of the kit allowed the Audiologist to gain meaningful information about the child's perspective of their hearing loss					
Engagement of the child took some time before useful information was elicited					
The videos (tool in use) highlight that the kit helps the child's communication skills, self-advocacy, and self-efficacy					
The videos (tool in use) highlight that the kit can effectively be used to give the hearing-impaired child's communication strategies in difficult listening situations					
The videos (tool in use) highlight that the kit can be effectively used for all three environmental boards (i.e. home, school and outdoors)					
The videos highlighted limitations in the design of the boards/moveable objects					
The videos highlighted the kit's great ability for the child to externalize their hearing loss					

3. If you have any other comments about the videos, please discuss them below.

Click here to enter text.

4. Do you think this would be a useful kit to be used in Audiology appointments or by other professionals such as Psychologists or Teachers of the Deaf/Visiting Teachers with hearing-impaired children? Why/Why not?

5. Please rate the following aspects of your own experience with paediatric rehabilitation and your perspectives (please click the box you agree with – select only one):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My Audiologist/s when I was a child had a good understanding of my hearing loss					
There is a gap in Audiologists' knowledge of the hearing loss from the child's perspective					
Current methods in counselling of hearing-impaired children are adequate					
There needs to be an alternative method for the counselling of hearing-impaired children					
I was given adequate strategies on how to explain my hearing loss to others by my Audiologist/s when I was a child					
I was given every-day conversational repair strategies as a child					
My hearing loss was adequately explained to me (and directly explained to me) by my Audiologist/s when I was a child					
I was given adequate strategies on how to deal with difficult listening situations by my Audiologist/s when I was a child					
I was given adequate self-advocacy strategies by my Audiologist/s when I was a child and I felt I was able to self- advocate					
I was adequately prepared to manage my hearing loss at home as a child					
I was adequately prepared to manage my hearing loss in school as a child					
I was adequately prepared to manage my hearing loss in social situations as a child					
My communication challenges were adequately addressed by my Audiologist/s as a child					
There is a gap between the counselling of hearing-impaired children by Paediatric Audiologists and Paediatric Psychologists					
Counselling of the child is within the boundary of audiology expertise in rehabilitation (i.e. not just amplification and audiological test based)					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	Audiologist	Psychologist	Teacher of the Deaf	All three	Other (please specify)
Who should address the counselling needs of hearing-impaired children?					

6. Were there issues that were not addressed in your rehabilitation as a child? If so please describe. Click here to enter text.

7. Please rate the following aspects of your own experience with school, social and home life <u>AS A CHILD</u> (please click the box you agree with – select only one):

box you agree with – select only one):	Strongly	Disagree	Neutral	Agree	Strongly
	Disagree			0	Agree
AS A CHILD AT SCHOOL (Focus on Primary School age)					
I was adequately prepared for discussing hearing issues/difficulties with my teachers					
I was adequately prepared for discussing my hearing issues with my peers					
I felt able to self-advocate at school					
I readily self-advocated in class					
I readily self-advocated in the playground					
I needed strategies for how to cope in the classroom					
My Visiting Teacher of the Deaf/Teacher of the Deaf adequately helped me when I had difficulties in school					
I was not confident and was a shy child in class					
I used communication strategies at school to help me					
I knew how to adequately discuss things such as notetakers and education assistants to other students and teachers					
I had a full understanding of the benefits and limitations of amplification at school					
I felt peers were willing to help me when I needed assistance					
I felt accepted by students at my school					
AS A CHILD AT HOME					
I adequately discussed my hearing difficulties with my parents					
I adequately discussed my hearing difficulties with my siblings					
I was encouraged by my family to self-advocate					
I felt able to self-advocate at home					
I used communication strategies at home to help me					
I had a full understanding of the benefits and limitations of amplification around the home					
I felt included in the things my family did together as a child					
I felt left out of family conversations					
AS A CHILD DURING SOCIAL ACTIVITIES					
I felt left out as a child					
I felt okay explaining to others that I am deaf or hard-of-hearing					
My self-esteem was excellent as a child					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I found self-advocating for inclusiveness difficult					
I was adequately prepared for communication strategies in social situations					
I tended to not discuss my hearing loss or difficulties with other children					
I felt able to self-advocate in social situations					
I used communication strategies in social situations to help me					
I had a full understanding of the benefits and limitations of amplification in social situations					
I felt okay asking for what I wanted at public places e.g. shop assistants, etc.					
I felt embarrassed asking people to repeat themselves					
As a hearing-impaired child it was easy for me to start talking to people I didn't know					
I felt I missed out on activities and things I wanted to do					

8. Please rate the following aspects of The 'My World' Kit (please click the box/es you agree with – you may select more than one):

	3-5 years	6-9 years	10-12 years	3-12 years	Other (please write)
The most appropriate age group for the Kit is:					Click here to enter text.

	Screening and Referral (e.g. to Psychologist)	Counselling on hearing strategies, social-emotional counselling	Both	Other (please write)	There is no use clinically for the kit in practice	
The kit should be used by Audiologists for:						

	Annual Reviews	Hearing Aid Reviews	Cochlear implantation or other candidacy assessments	Periodic educational assessments	Other (please write)
When and under what circumstances should the My World kit be used: (you can select more than one)					Click here to enter text.

9. What other uses do you potentially see for this kit in rehabilitation? Click here to enter text.

10. Please rate the following aspects of The 'My World' Kit (please click the box/es you agree with – you may select more than one):

	Audiologist	Psychologist	Teacher of the Deaf/Visiting Teacher	All of the selection	None/Other
Who do you think should be using this kit					Click here to enter text.

- 11. Do you think parents could have a role in the use of this kit? e.g. Filial therapy? (Filial therapy is a closely related form of child-centred play therapy that involves the parents or carers). Why/Why not? Click here to enter text.
- 12. Please rate the following aspects of The 'My World' Kit (please click the box you agree with select only one):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The kit items are adequate in number and form					
The packaging of the kit should be different for different age groups (i.e. customisation and item units)					
The kit needs more development overall					
A multi-disciplinary approach to the use of this kit would be beneficial					
There is a NEED for the My World kit clinically					
This kit could enhance/improve the outcomes of paediatric rehabilitation					
The kit could work well using photos for inspiration					
Open-ended questions work well with this kit					
This kit would be useful in giving the child strategies and developing their self-efficacy, self-esteem and confidence					
I wish there had been a kit available such as this when I was younger					
I think that a kit like this would have helped me					
I think that this kit has the potential to help many hearing- impaired children					
This kit would be useful in obtaining BOTH the child's perspective of their hearing loss and helping the child successfully					
The methods to record and preserve information need refining if the kit is to be used clinically					
This kit will increase the effectiveness of counselling by Audiologists for hearing-impaired children					
I feel that this kit would be a useful counselling tool with hearing-impaired children who have very limited language					
I feel that more paediatric counselling skill resources for Audiologists are necessary					

13. Please rate the following aspects of The 'My World' Kit (please click the box you agree with - select only one):

	YES	NO	UNSURE
Do you this the My World kit can be effectively used clinically as it is currently presented			

Why/why not?

Click here to enter text.

- 14. Do you see any drawbacks to the use of this kit? Please Explain. Click here to enter text.
- 15. Do you think such a kit would be successful for bridging the gap between the roles of Audiologists and Psychologists? Why/why not?

Click here to enter text.

16. How can this kit be framed so that it is more intuitive for a Paediatric Audiologist to use?

Click here to enter text.

- 17. Do you see different or more specific ways this kit could be incorporated clinically? Or uses for this kit by other professionals? Click here to enter text.
- 18. What additional skills or resources do you feel professionals in the rehabilitation of hearing-impaired children need? Click here to enter text.
- **19.** What do you feel are the needs of hearing-impaired children from the services of Audiologists, Psychologists and Teachers of the Deaf?

Click here to enter text.

20. What questions can potentially be addressed using the kit? If you can think of further questions in addition to those on the summary form please note them below. Click here to enter text.

Thank you for completing this questionnaire and for your participation in this research project. Please email the completed questionnaire to 20351824@student.uwa.edu.au