

GROUP BASED SUPPORT AND PARENT EDUCATION IN EARLY INTERVENTION: SUPPORTING THE UNIQUE NEEDS OF PARENTS WITH CHILDREN DIAGNOSED WITH HEARING LOSS

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Abstract

RIDBC Early Learning Programs (Hearing Impairment) provide early intervention services to families of children with hearing loss in a family-centred model of practice. RIDBC has a long history of supporting families on their parenting journey through a combination of regular, group-based parental support and early intervention, and comprehensive parent education sessions.

Group based and parent education sessions were developed by RIDBC in recognition of the unique needs and challenges confronting families of children who have been diagnosed with hearing loss. These sessions provide a blend of conventional early parent education which focuses on developing an understanding of hearing loss, basic audiology and strategies for developing communication with children with hearing loss, with more targeted family support. This targeted support focuses on developing attachment and engagement between parent and child, exploring and experiencing the emotions involved with early diagnosed hearing loss, and explores more complex but pertinent issues such as parenting children with hearing loss, and developing relationships between a father and child.

This paper reflects on challenges faced by families with children with diagnosed hearing loss, the model and structure of group and parent support RIDBC offers to families in response to diagnosed hearing loss, and the feedback provided by families participating in our program.

Introduction

The introduction of Universal Newborn Hearing Screening (UNHS) programs in Australia and throughout the world has resulted in the diagnosis of hearing loss in children occurring within the first weeks, if not days of a child's life. While there is significant evidence to support the developmental benefits of early diagnosis and therefore early access to intervention, less attention has been given to the impact that the process of early identification has on the families of these young children diagnosed with hearing loss (Young & Tattersall, 2007). More than 90% of children diagnosed with hearing loss are born to parents with normal hearing and thus in many cases these families have had limited, if any exposure to the world of deafness and hearing loss. Additionally, at the time of diagnosis, audiologists are often unable to offer families a trajectory for their child's future development based on their audiological data alone (Fehrer-Prout, 1996). Additionally, UNHS has brought about a change for families in the process of diagnosing hearing loss. No longer do parents come to discover their child's hearing loss through observation and interaction with their child, rather this discovery is made through medical intervention very early in their child's life. As a result, parents are not afforded the opportunity to experience their child as being "normal" in some cases for more than a day (Kurtzer-White & Luterman, 2003).

Research cites examples of families describing the diagnosis of hearing loss in their child as stressful and comparable to the experience of grieving a death or loss (Fehrer-Prout, 1996; Kurtzer-White & Luterman, 2003). The parents' "loss" is for the loss of their

typically developing child (Kurtzer-White & Luterman, 2003). However, the grief experienced with the loss of a loved one is often finite; the grief, sorrow and other emotions experienced by parents of children with diagnosed disabilities is often non-finite and early intervention programs must acknowledge this as such (Kurtzer-White & Luterman, 2003). At the same time as experiencing this weight of diagnosis, parents must simultaneously develop an understanding of their child's hearing loss as well as develop skills and strategies to support their communication development.

In acknowledgement of the unique grief and emotions that families may experience, the importance of early intervention programs addressing the emotional needs and coping strategies of parents has been highlighted in a number of studies (Yoshinaga-Itano, 2003; Young & Tattersall, 2007; DesJorges, 2003; Kurtzer-White & Luterman, 2003). According to Moeller (2000, in DesJorges, 2003, 89), the 'success of children who are identified as deaf and hard of hearing is critically impacted by parents' reaction, acceptance, and advocacy for their child'. Kurtzer-White & Luterman (2003, 232) indicate that while early identification of hearing loss and access to early intervention is correlated with more positive developmental outcomes for children, the grief and coping skills of parents are also a 'significant variable in...attaining outcomes for children with hearing loss'. Additionally, Yoshinaga-Itano (2003) highlights the importance of developing early intervention programs which support the emotions that families experience in the wake of diagnosis.

The Baby Tree Program

The Royal Institute for Deaf and Blind Children (RIDBC) has been providing services to children with hearing and vision loss for over 150 years. Current services address the needs of children from birth to 18 years of age across early intervention, preschool, and school based programs. The RIDBC Early Learning Program (ELP) is one of RIDBC's largest service areas providing early intervention to families through a combination of weekly individual sessions, group early intervention sessions, parent education sessions, and supporting integration in mainstream early learning environments.

Following the introduction in 2002 of the UNHS program, SWISH, in the Australian state of NSW, RIDBC was faced with the new and unfamiliar prospect of supporting children and families whose hearing loss had been diagnosed at birth. In response, a dynamic program of support for the families of newly diagnosed babies was developed. This was comprised of weekly individual home based sessions with a dedicated infant Teacher of the Deaf (ToD), in addition to a fortnightly group based Parent Infant Group (PING) which was facilitated by this same ToD with the support of an educational psychologist. This group focused on acknowledging and valuing parents' knowledge of their babies, the development of parents as their child's first teacher, and offered information and supportive encouragement to parents to develop their baby's communication through nurturing interaction and play. Parents were encouraged to join the group at any time during baby's infancy, and attendance concluded once the child was physically ready to move to the next Early Learning Group which focused on toddler play and language. The PING was positively received and well attended by parents. Over time, and more acutely from 2011, a considerable drop in PING attendance was observed. Families reported that life was busy, travel was becoming increasingly difficult, and that often many appointments needed to be attended, all of which impacted on their ability to attend PING regularly. Inconsistent and low attendance resulted in a noticeable lack of cohesion in the group which made the sharing of

experiences and bonding as a cohort challenging. It was also observed by the ToD's conducting individual sessions, that families of newly diagnosed babies appeared to find natural interaction and attachment with their child challenging. In some cases it was also observed that the grieving process following the diagnosis of hearing loss was prolonged and resurfaced at milestones such as birthdays and starting educational settings. It was thus determined by RIDBC that more targeted and specific group support for families with newly diagnosed babies was needed.

As discussed, research has indicated a strong correlation between parental coping, acceptance of diagnosis and positive involvement in early intervention with better developmental outcomes for children. The need for programs to support families in addition to children is well documented. Parents of children with hearing loss can often experience feelings of isolation and a desire to connect with other families who have a similar, shared experience (Hoffman 2012). Fehrer-Prout (1996, 163) suggests that 'the amount of support mothers received ... contributed significantly to the quality of later mother child interaction'. Additional reflection by RIDBC staff on attachment revealed that attachment and bonding between parents and a child with a disability presents additional challenges for families, as parents have to persevere to develop a sense of attachment to their child. This is supported by Eakin, 2012 in her reflections on the challenges families' of children with disabilities face in developing attachment and bonding. In the case of children diagnosed with hearing loss, a parent also needs to make an extra effort to communicate with their child. These factors were at the forefront when considering the importance of parent support and sparked the development of a new RIDBC model of group based parent support in its ELP.

With this information in mind, RIDBC offered a parent infant group in a slightly new format. This new group, The Baby Tree, was developed with the goal of supporting families through the acute stages of diagnosis in a format that was easily accessible, required only short term commitment and provided effective parent support with individual follow up if required. The Baby Tree was offered weekly for a set period of 8 weeks, with new families invited to attend at the beginning of a new 8 week cycle to facilitate rapport building between parents, and ensure that each group bonded and moved through as a cohort. Families were asked to commit to all 8 sessions, as each session built on the next. The group was facilitated by both an Early Childhood Teacher of the Deaf and a Clinical Psychologist, and involved a maximum of 7 families with their babies, to keep the group intimate and ensure individual support was offered where appropriate.

The aims of The Baby Tree included the strengthening of attachment between babies and their parents; the establishment of an initial network of support for parents with a shared experience of hearing loss; the promotion of a sense of belonging and connectedness to a group and the enhancement of parental skills and knowledge through the sharing of information and guided support. The group was developed in the context that parents know and understand their child best and group facilitators aimed to further support this.

The core components of each Baby Tree session were a time for meditation and relaxation, a guided music, movement and playtime for parents and babies, information and guidance on communication development in infants, and a free "chat time" for parents over lunch to provide opportunities for parent-led discussion. Additionally, rotating components included baby massage, reflections on hopes and dreams for each baby, the sharing of journeys post diagnosis and supported observation and response to baby's communication.

As The Baby Tree was developed to promote a sense of support and belonging for families, it was highly important that each family and child felt valued. While a large focus of the group was on developing attachment between parent and baby to aid communication development, a large emphasis was also placed on valuing the parent. As such, the group involved unique elements to achieve this including the provision of welcome bags and information packs for families; a home cooked lunch each week made by staff for parents; a room designed to create a protected circle to facilitate a sense of intimacy; and alternate arrangements made for siblings, to ensure the parent was able to focus solely on developing a relationship with their baby.

The Baby Tree facilitators met weekly to evaluate each session and plan for the following week. The following outcomes were observed over the 8 sessions by Baby Tree facilitators: Consistent attendance by all participants aided cohesion and the formation of relationships within the group; parents reported feeling safe to share their personal experiences and feelings, as well as offer mutual support to other parents; parents consistently reported that The Baby Tree was having a positive impact on their lives; parents maintained contact with their cohort following the cessation of their Baby Tree group through phone, email, Facebook, and facilitated reunion groups. Opportunities provided in both “free chat” and guided discussion for information exchange appeared to empower parents and the limitation on participant numbers ensured opportunities for individual follow up where issues arose around grief, developmental concerns and issues of device choice or functionality. Finally, continuity of attendance ensured ample opportunities for reinforcing strategies with families to support listening and language development in their baby.

Parents who participated in the second Baby Tree cohort were given the opportunity to provide written feedback to facilitators through an anonymous survey, which comprised 5 open ended questions and 3 rating scales. 7 from 7 surveys were returned and responses supported outcomes observed by facilitators in addition to reflecting the perceived needs of families as outlined in the literature. Participants were questioned as to what they hoped to achieve by attending The Baby Tree. Responses included “Meeting parents on the same journey to share experiences”; “[to] Meet other parents and children with similar issues, hopefully living in my area”; “To be able to relate to other parents and children”. These responses support the work of Hoffman (2002) which suggested parents of children with hearing loss can often feel isolated and may express a desire to connect with other families who have a similar, shared experience. Participants were asked to articulate any aspects of The Baby Tree that made them feel supported in their play and interactions with their child. Responses included “Meditation and information each week”; “Support from other mums”; “Examples of games and activities to play”. These responses indicate that the unique elements of The Baby Tree supported parents to feel valued and were appreciated by participants. Additionally, participants were asked what they liked best about The Baby Tree sessions. Responses included “Relaxing with other parents”; “Meeting another parent with a child with LVAS”; “Hearing a guest speaker talk about her story”; “Problems share[d]”. It can be assumed that these responses indicate that participants best enjoyed opportunities to share experiences with other parents who have a similar shared experience of hearing loss. In terms of level of confidence in supporting their child’s communication development at home, 6 out of 7 parents indicated an increased level of confidence on the rating scale following their attendance at The Baby Tree when compared to their pre-attendance ratings.

Based on feedback provided by participants and observations made by group facilitators, future Baby Tree groups will include elements of the following to further enhance opportunities for connection within the group and maintain a sense of belonging: combining both technology based and face to face ongoing support through mediated forums, and online reunion groups or individual support; opportunities for “graduate” Baby Tree families to come to attend new Baby Tree groups and share their journeys with new families; and rotating staff members trained in psychology from cohort to cohort to provide different perspectives to each group.

Conclusion

Following the inception of UNHS programs in Australia and many other parts of the world, the provision of early intervention services has undergone significant change. Responsive and innovative services should be, and largely are, provided to young children diagnosed with hearing loss, so as to maximise their potential for development. However, to ensure the long term success of the child, it is essential, when designing and delivering services, that those services also consider the unique needs of the parents and families of those children.

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