

Where Are We Now and Where Do We Need To Be? A Perspective From New Zealand

David Foster

Abstract

We know that collaboration is important. But how does it happen in the real world? Can it be measured? And what would be measured if families truly had the opportunity to lead changes in the way education happens? New Zealand has one of the most devolved education systems in the world (OECD 2012). The real story that New Zealand has to offer the world is the unique operation of its special education systems and in particular the governance and leadership of its schools for Deaf - the interaction with parents, the close collaboration between parents and professionals, the measurement systems used with the children and the constitution of the Board of Trustees. Parents' feedback has confirmed the importance of four themes when developing and delivering services to Deaf and hard of hearing infants and their families: timing, relationships, processes and opportunities. This presentation explores what has been learned in a system where parents are genuinely in the driver's seat.

New Zealand has one of the most devolved education systems in the world (Nusche, 2012). From the beginning of October 1989, New Zealand schools have been governed by parents, elected every three years by postal ballot. Parents as trustees have become the embedded paradigm for school governance. The function and powers of the Board of Trustees are clearly stated in the Education Act (1989):

- *A school's board must perform its functions and exercise its powers in such a way as to ensure that every student at the school is able to attain his or her highest possible standard in educational achievement.*
- *Except to the extent that any enactment or the general law of New Zealand provides otherwise, a school's board has complete discretion to control the management of the school as it thinks fit.*

In a New Zealand school, the Principal is the chief executive. The Principal has complete discretion to manage the school's administration on a day to day basis provided that this power is executed within the laws of the land and follows the policy direction of the controlling board. Simply put, the Principal and staff are employed by parents to work for their children. The Principal and staff are required to report to the Parents and the Ministry of Education about the achievement of students.

In October of 2012 the Minister of Education approved a revised constitution for the governance of New Zealand's two Deaf Education Centres. Under this constitution the governance of the two Deaf education Centres was consolidated under of a single nationally elected board of trustees. The Board of Trustees mandate was also extended to responsibility for all students enrolled at or receiving services from the two Centres. The decision to combine the Board and extend its mandate was enacted following nearly ten years of discussion at national consultation forums and eighteen months of community consultation specific to the proposed governance change. There is an adage that says, what gets measured, gets done, and in the New Zealand system parents have this opportunity. Parents get to decide what gets measured and therefore they get to decide what gets done.

The Combined Board has determined that four priorities will drive the activity of its first three year term of office:

1. The development of a national database of deaf students, both enrolled at and receiving services from, the Deaf Education Centres.
2. Reporting an accurate picture of deaf students' achievement in this emerging national context.
3. Strengthening connections for students and staff through applied technology; and
4. Maintaining a community that celebrates the unique cultural and linguistic identity of deaf children.

Each Deaf Education Centre continues to execute its responsibilities on a geographical basis by providing five core services:

- The operation of a specialist school for the deaf (Grade K through Grade 12).
- Residential hostels to facilitate attendance at the school.
- Itinerant (visiting) teacher services on a regional basis.
- Bilingual preschools; and
- Development and delivery of a range of specialist resource and technical services (including audiology for enrolled students and repair and maintenance of hearing aids and FM Systems for all students in the Centres geographical region).

Joint venture agreements are in place to ensure collaboration in the delivery of services for cochlear implanted students. A series of nationally coordinated pilot projects is currently monitoring the implementation of collaborative services for deaf infants identified through newborn hearing screening. Parents (the governing trustees) have an absolute expectation of involvement in all strategic and policy discussions related to the development and delivery of services to deaf students. Parents are present at all major decision making discussions led by the Ministry of Education.

Philosophical Perspective

In Maori there is a concept known as *whakatauki* which is both a traditional proverb and call to action:

*Tungia te ururua
Kia tupu whakaritorito
Te papa o te harakeke*

Translated this *whakatauki* challenges a community to ensure that they clear away anything that stops growth; it reminds one that growth comes only from the centre – the most vulnerable part of the plant; and that eventually the plant will return to the earth. Our KDEC staff subscribe to *whakatauki* as it provides a context that relates to the growth of the deaf child. The education community's commitment to *whakatauki* is captured in the KDEC logo. The koru (symbol of growth) at the Centre represents the children. The "leaves" to right and left form the New Zealand Sign Language hand-shape for communication and represent the partnership between parents and professionals that provides a caring learning environment. The weaving at the base of the logo acknowledges the strength of combined action and also captures the notion of collaboration as history and traditions. The open space at the top of the logo highlights achievements as a focus while the overall design is, in abstract, a letter "K"



The KDEC learning community comprised of children enrolled at, or receiving services from teachers of the deaf, multi-disciplinary specialist professional teams as well as administrative and para-professional staff. Every week the staff works with over 530 children; the vast majority of whom rely on audiology for their access to language, and therefore, their access to learning.

How Are We Doing?

This paper seeks to examine perspectives of parents. In the context outlined above this is a cohort of parents who have firmly held expectations of involvement with, and to a certain extent influence over, those who are providing services. In short New Zealand parents expect to be fully involved in every aspect of their child's

growth and development. In the context of audiology for young deaf children how would these expectations be expressed and how would services respond to these expectations? What would collaboration really look like – how does it happen in the real world? What would be measured if families truly had the opportunity to decide? Would their views change the way you worked?

Professionals generally exhibit a strong sense of identity in the language they use to describe their practice. The concepts evident in audiology professionals' self-description are fascinating. There is a reliance on tools, skills and strategies that can be brought to bear in a given situation. Through the years, much of the Phonak Sound Foundations Conference series has been focused on technological advances, technical skills and professional practices and guidelines. Expertise in these areas is vital to advances in the field and the access of deaf children. This paper respectfully proposes that a different choice of words might emerge in the language used to describe success in audiology if a different group of people was asked to contribute to the definitions of effective practice (<http://hearingcareblog.com/2013/10/22/doctors-of-audiology-emphasize-care-options>).

Four Themes

An increasing data base of empirical research is capturing the “narrative” of families in these changing times (Young and Tattersall, 2007) and articulates, on behalf of families, the expectations and experience of service for deaf infants and children. From this literature, based on family's views, four themes emerge as significant to the discourse that needs to permeate the relationships between parents of deaf children and the professionals from whom they receive services.

The first theme is **TIME**; the time in which it is possible to identify a child's deafness. In New Zealand prior to 2010 the average age of detection was in excess of 36 months! (Digby, Kelly and Purdy, 2010). Theoretically it is possible to identify and confirm deafness as early as nine weeks of age. Parents express positively the impact of their child's deafness being “picked up” early.

This shift highlights a second theme, the **PROCESS**; the process by which parents arrive at confirmation of their child's deafness. Prior to universal newborn screening, it was likely that parent's observations of their child by 24 to 36 months of age, would suggest to them that their child might be deaf. Now, newborn hearing screening can speed parents to that place in one tenth of the time. While this change speeds up the possibility of

action, it can also lead very quickly to a sense of frustration if parents perceive inactivity from those responsible for providing services.

Combined with more timely access to identification, and more active follow-up, the habilitation processes create the potential to positively impact on the fundamental familial **RELATIONSHIP**. This third theme of relationship is concerned with parents who formed relationships with their child whom they subsequently found to be deaf. By confirming their child's hearing loss almost immediately at birth, parents have the chance to form a better relationship which acknowledges their child's deafness, as they are learning to know their baby.

And finally, the fourth theme is **OPPORTUNITIES**; the knowledge that their baby is or deaf, coupled with the technologies of the 21st century, is shifting the expectations of relationships between parents and professionals. This compels us to view new opportunities for involvement within a new framework.

Parent's Perspectives

In order to confirm these four theoretical perspectives, a range of parents were invited to consider and respond to two questions. Participants were invited to respond either as part of a group discussion (with Auckland Parents of Deaf Children, Inc.) or individually via a written survey. The responses were synthesised according to the theme that they challenged or reinforced.

1. Describe a time when you just knew that your audiologist “got it” when engaging with you or your deaf child?
2. What are the most important things for professionals to remember when dealing with families of deaf children?

Parents' responses to these questions provide insight into how the four themes play out in the daily life and experience of a range of New Zealand parents over the past 12 years. The actual words of the parents, reprinted below, provide an opportunity for us to assess not only where we are as professionals, but also where we might need to be directing our future efforts:

Time

- *It is hugely important for an audiologist to act fast, particularly when dealing with a pre-lingual child.*

- They need to be careful to see the child and not just the condition. It is easy to put parents' backs up by focusing solely on the deafness.
- Over the years I felt uneasy when hearing was being tested, how good was the equipment, did the audiologist have the experience to understand the testing. It's important we know what each test is for and how the results are worked out.
- The audiologist and I were the primary participants at the appointments. The audiologist, began to shift the interaction so that she and my daughter, at about aged eight, were now the primary participants in the appointment.
- My child would be going to an audiologist for the rest of her life, as a parent I needed to begin to shift my participation to its' right place - as a support person.

Process

- Without any experience of hearing loss before, I was quite shell shocked when dealing with a groggy infant coming around from sedation and then to be delivered this news by the audiologist while we were in the recovery ward. He had to rush off and so he didn't give us much information.
- Parents are very much still in shock about their child's hearing loss. Often parents do not understand what is being said to them, the words and what it all means, they can only retain so much and learn so much, they go into overload.
- Whatever solutions are presented for a child, they have to be manageable for the family within their social contexts. It is reasonably common for fathers to go into denial about their child's deafness.
- A relationship of trust between the audiologist and parents is one of the most essential elements of success with families. Without trust, families will not share essential information e.g. how much are our kids actually using their technology?
- Whenever I have received an answer or advice I haven't been comfortable with I always say to myself - would things be different if I stand my ground and refuse to leave until we've talked this through.
- Audiologists are people you have to trust...Audiologists may unintentionally project a negativity of the situation on to vulnerable parents.
- Please consider what language you are using: time of identification (NOT diagnosis), involvement (NOT intervention). Is deafness really bad news?
- Never say "Or" when discussing the options the child

and family can use. Say "AND" this "and" that are options.

Relationships

- I think that audiologists should make it a priority to have the fathers along for the journey as soon as possible.
- Be incredibly careful to see the child as part of their family.
- Really listen to the instincts and issues raised by the parents of the deaf child and to take those concerns seriously. It is important for audiologists to understand the implications of hearing loss from the point of view of how my family needs function.
- The first audiologist was the most truthful and made the most difference for us, he answered my questions with complete honesty.
- My audiologist gave me the names of two families and after a few weeks I rang them. These parents gave me further determination. I have been actively involved in parents networks ever since!!

Opportunities

- My Daughter has the right amplification and she is effectively amplified for every waking moment of every day. Sadly so often I hear and see families whose children do not wear their hearing aids and or have not opened all the boxes the audiologist have given them.
- Parent's need to be experts on the equipment. Parents should know that they need to be actively helping their child's listening skills and acquisition of language.
- Every day counts in terms of making up for the delay in language development that may have occurred. We must deal with this as a matter of urgency.
- The audiologist in a really respectful way that helped me to understand that the most important 'player' at these appointments was my child .
- I recall my first positive dialogue with an audiologist was when we accessed the KDEC audiology clinic and worked with Leslie Searchfield.

Paediatric Audiologist at KDEC

Leslie Searchfield is the paediatric audiologist at KDEC. Leslie has generously agreed that this presentation may quote her testimonial on the four themes being explored:

On **TIME**: "I believe I can remember every child with a severe to profound hearing loss that I have identified.

Sitting with families through all the assessment is time of significant highs and lows. The most important thing when working with families is to take things a bit slow and where possible go at the pace they set"

On **PROCESS**: *"Prior to newborn screening, the parent generally knew the child was deaf. Put the child at the centre of all contact. Each family is unique. Although there will be similarities among many they all have their own background and perspective about deafness and you need to recognise and value this. Watching the family work through one bad news situation after another and still managing to function is an experience I will never forget!!"*

On **RELATIONSHIPS**: *"These experiences are very emotionally charged. Diagnosis of a brand new baby appears more difficult and shocking for the family, and it seems to take a bit longer for the family to accept. You need to be empathetic. Try to encourage family involvement. More than once I have had parents comment that I am the first professional who walked into the room and knelt down and engaged their child."*

On **OPPORTUNITIES**: *"Take time to talk and interact with the child. The most important thing we can do is increase the self-esteem of both the child with hearing loss and their closest caregivers."*

Leslie recalls a rewarding moment with a young boy who was doing very well with his CI. Leslie was talking with the boy's mum, but the young boy kept interrupting his mum's conversation. Finally, the mum turned to her son and said, "Please be quiet. I am talking with your teacher." Then the mum suddenly got dead silent, began tearing and laughing, and said to Leslie, "I never imagined that I would be telling him to be quiet!"

Concluding Remarks

It is easy to get distracted by career acknowledgement, reputational development, status and research, each of which can be good for business and professional growth. Professionals, whether Principals of Deaf Education Centres or Paediatric Audiologists, need to remember daily that their work is about deaf children, their relationships with their parents and the children's futures. And, that these futures are brighter now than at any previous time in history.

Professionals in audiology and deaf education who want to maintain focus on the desired trajectory of services for deaf children need to base their work on the views of parents. Parents' views will confirm that services need to honour the child as a member of a family group and the child as a viable participant in a community. Audio-

logical access enables the deaf and hard-of-hearing child to participate more fully in their community and creates opportunities for increased language development and social engagement. Parents' views will constantly remind professionals to describe technical development and research breakthroughs in terms of the improvements that can be gained for deaf children to become well-adjusted deaf adults.

Deaf children have the same rights to participation and engagement as their hearing peers, but deaf children do have distinctive needs. They need access to services that recognise their individual and special needs and services that will promote them becoming independent and self-determining members of society. Education of deaf children is successful when based on a partnership between the children, their families and those responsible for the provision of services.

To conclude this reflection in the languages of Aotearoa / New Zealand is the call of our deaf children. It has brought us all together:

*Ko te kaupapa ke hoki te ora tanga
o nga tamariki turi
No reira kia ora mai ano tatou*

Acknowledgement

As the Principal of Kelston Deaf Education Centre (KDEC) in Auckland, New Zealand, I wish to express my heartfelt thanks to the Phonak Sound Foundation Conference organising committee for the opportunity to share one perspective on a New Zealand education system.

*Ki te Komiti whakahaere he mihi nui,
he mihi aroha ki a koutou mo te karanga
mai i ahau.
Ko David Foster taku ingoa te Tumuaki
o te kura matua o Kerehana mo nga
tamariki turi.
Tena koutou, tena koutou,
tena koutou katoa*

References

Digby, J.E., Kelly, A.S., Purdy, S.C. (2011). Hearing loss in New Zealand children: 2010. New Zealand Audiological Society, Auckland, New Zealand.

- Education Act of New Zealand (1989). New Zealand Legislation. (<http://www.legislation.govt.nz/act/public/1989/0080/latest/DLM179565.html>).
- Kelston Deaf Education Centre Audiology. (http://www.kdec.school.nz/education/specialist_services).
- Nusche D. et al. (2012). *OECD Reviews of Evaluation and Assessment in Education*. New Zealand, 2011. OECD Publishing.
- Young, A. and Tattersall, H. (2007). Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Oxford Journal of Deaf Studies and Deaf Education*. (<http://idsde.oxfordjournals.org/content/early/2007/02/02/deafed.en1033.full>).