

Families' Talanoaga About Building Relationships With Special Education Services

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Abstract: This research was conducted in New Zealand in 2012 as a contract research project funded by the Ministry of Education. *Pasifika Education Research Priorities* (Ministry of Education, 2012a), the Ministry's current priority for Pasifika research in education, has highlighted the goal of improving engagement and satisfaction with Special Education (SE) services for Pasifika young people and their families. This was explored from the perspectives of parents and families of young children of early childhood and primary school age primarily within the Manukau area. We used *talanoa* (conversation/telling stories) (T. M. Vaioleti, 2006) as the framework for collecting data. This approach enabled families to share their own stories in depth with the interviewers. We concur with Sapon-Shevin (2007) who argues that the term *inclusive education* means ensuring participation by all children who may be excluded by ability, gender, socio-economic status, ethnicity or other categories. Pasifika families in this research experienced personal and systemic barriers to accessing services. Overcoming systemic barriers such as the need for wider support for parents, families and communities are one of several priorities that came out of this research. This includes providing professional development for staff in early childhood centres and schools to identify and support families with children with special needs. Service providers also need to focus on building relationships and be culturally sensitive and aware so they can support intercultural communication and understanding.

Key Words: Pasifika research, inclusive education, family services

Introduction

This research was conducted in Aotearoa New Zealand in 2012 as a contract research project funded by the Ministry of Education. The project arose from the document *Pasifika Education Research Priorities: Using Research to Realise Our Vision for Pasifika Learners* (Ministry of Education, 2012a). One of the priority questions identified in the document is: "How can we better understand special education from the perspectives of Pasifika families?" The purpose of the research was to better understand Special Education (SE) from the perspectives of Pasifika families in order to increase their engagement and satisfaction with SE services provided by the Ministry. The *Pasifika Education Plan 2013–2017* (Ministry of Education, 2012b) puts Pasifika learners, their parents, families and communities at the centre of all activities.

The research was qualitative and involved in-depth interviews with 18 Pasifika families with children of early childhood and primary school age who have special educational needs; the families included both those engaged and not engaged with SE services. Ten professionals whose role involves working with Pasifika children with special education needs and their families were also interviewed. In addition, two focus groups were held to explore themes emerging from the interviews with the Pasifika families and SE professionals.

The five research questions aimed to identify the strengths of current service provision and any barriers to accessing SE services for Pasifika families. Other questions were about the extent to which cultural perspectives on disability and SE, as well as the low numbers of Pasifika professionals, affected engagement and satisfaction with SE services for Pasifika families. Participants were also asked for suggestions as to how SE services could be improved to increase engagement with and satisfaction for Pasifika families.

The terms *inclusion* and *inclusive education* are defined differently in different contexts, and underpin our current view of SE services. Some educators argue that the term inclusive education means ensuring participation by all children who may be excluded by ability, gender, socio-economic status, ethnicity or other categories (Sapon-Shevin, 2007). Ainscow (1999), however, perceives inclusion as a process of removing barriers for all children. Children and young people have the same basic human rights that adults have, but as a vulnerable population group, children with diverse needs have the added need for protection and promotion of their rights. This is a view that is fundamentally relationship driven. This perspective connected well to the way we reached out to participants through our existing relationships within the local communities from which our participants came. This relationship-driven methodology was based on *teu le va* (Anae, 2010). The principles within *teu le va* emphasise the fostering of respectful, collaborative relationships between researchers, between researchers and policymakers, and between researchers and all those involved in any given research project in the building of a sound knowledge base for Pasifika education (Airini et al., 2010).

Talanoa as a Qualitative Data Research Methodology

Given that all families and the majority (80%) of professionals were Pasifika and included seven Pasifika cultural backgrounds, a blend of two different Pasifika research methodologies were used in this research project. Because Pasifika cultural identity is relational rather than individual, relationships were nurtured during the research. *Teu le va* has already been discussed, and the second methodology used was *talanoa* (T. M. Vaioleti, 2003, 2006) which also acknowledges the paramount importance of building and maintaining good relationships between the researchers and participants. *Talanoa* is the everyday use of open and inclusive communication, which allows people to tell their stories and incorporate emotion and spirituality (T. M. Vaioleti, 2006).

Talanoa allows for the co-production of knowledge. Talanoa is founded on deeply ingrained Pacific values and therefore it is easily recognisable, and is seen as an acceptable and culturally safe way to engage with Pacific people in research (L. Vaioleti, 2013, p. 1).

Eighteen family participants from seven ethnic groups were recruited through the Lalaga (Mauigoa-Tekene, Howie & Hagan, 2013) approach (Samoan word that relates to the process of weaving a table or floor mat); eleven of these families have children who were engaged in SE services while seven families were not. Of the eighteen families, eight were New Zealand-born and ten were born in the Islands. All families were interviewed by an interviewer from their own cultural background. Eight of the family interviews (44%) were conducted in the participant's first language and all were given a koha to acknowledge their contribution to the research. While there was an interview schedule with questions framed around the research questions provided by the Ministry of Education, the questions were used as a series of prompts for interviewers to encourage participants to share their story. The first prompt was "Please tell your story in your own way...". Further prompts were used when the interviewer noticed that participants had not commented on one or more of the research

questions. The interviewers found that *talanoa* helped to reduce the distance between the participants and the interviewer, although distance was less of an issue with the Pasifika professionals we interviewed. We acknowledge the cultural capital and relationships in their communities that the participants brought to each interview.

Findings and Discussion

This paper will focus on the findings from two of the research questions; firstly the barriers that families experienced when accessing SE services and secondly suggestions for how SE services could be improved to increase engagement with and satisfaction for Pasifika families. The *talanoaga* (having a conversation; sharing stories) is represented through quotations, and a vignette from one of the parent participants will be used to further illustrate this.

The first question that will be discussed uncovered some barriers, both personal and systemic, to accessing SE services for Pasifika parents and/or caregivers of young people with special education needs. It must be noted that despite the strong emotional content of stories about barriers families experienced, there were also several comments about strengths in the service provision, including some families who felt that early intervention and support in particular was a strength of SE services. Where support staff in centres and schools were skilful and built good relationships with a child and family, parents were very satisfied.

Personal barriers included language and cultural barriers and families' lack of knowledge of available SE services. A further subtheme that emerged is economic barriers, which included lack of transportation and the cost of care for children with special education needs.

Systemic barriers included those within SE services and the lack of more holistic support for families, including their extended family, whose children had special education needs. There was also a sense that SE services were focused primarily on the child whereas families might need, for example, counselling and/or support to meet the additional costs of raising a child with special education needs. Some families reported poor relationships between services and families, lack of coherence and communication between professionals and between professionals and families, and lack of cultural intelligence and sensitivity. There was a strong feeling from families that if they did not agree with the professionals who supported them, they might be withdrawn from the service. Pasifika professionals reported that both early childhood and school teachers sometimes lack the skills, knowledge and capacity for identifying and referring children to SE services. Indeed, six families in the study were not engaged with SE services because their children's early childhood teachers had not advocated for referrals. Through this research, six of the seven non-engaged families began the process of engagement with SE services.

Although most families shared these barriers as a limitation to engagement with SE services, the following feature story or vignette highlights some of these barriers to participating and accessing SE services. Ofa's story is a powerful vignette of the grief and challenges Pasifika families may experience when a child is diagnosed with special education needs. Ofa is a New Zealand-born Cook Island/European woman and a solo parent of four children. Three of her children are engaged with SE services and have been diagnosed with autism. Ofa's story highlights the need for professionals to behave with sensitivity and to be aware of both cultural norms and the personal support families might need.

Ofa's Story (Talanoa, Ofa, 20 June 2012)

When my [first] son was diagnosed, we were all brought into ... the room and there was a psychologist, speech language therapist and what was the other? ... Anyway, the first time that I've met them. They've gone over all the notes from Group Special [Education]. They went away, they've observed my child, they came back and just bluntly told me that he has autism and that was it. And I sat there and he ... handed me some tissues, but just the way he said it. I was devastated and I just sat there for probably a good – half an hour and said nothing and I was crying. ... it was like the way they delivered it to us it was just cold, it was so cold.

I thought it was the end of the world when they told me ... and then I looked over at their ... dad and he was just in shock – he was in shock because they went out, they deliberated and they came back and they just said, "Oh well, yeah, sorry to tell you but your child has autism. Do you know what autism is?" And I just sat there and heard the word autism and like I just thought, "Oh my gosh." I have no recollection of what autism is – all I remember is a kid rocking – that's all I could see. And then I looked at my son and I started crying and like I just sat there and didn't say anything to them for about half an hour.

And they wanted me to go because they had another appointment.

But there were like unanswered questions that I had, but I couldn't [ask the questions] because I was trying to get over the emotion. And from there ... I didn't know, I was just so numb that I walked out of there with all these unanswered questions. ... there was nothing told to us prior to that and I just ... you think if you go to Super Clinic – it'll just be for his ears again. There was no warning of what we were going to do.

... Who was I going to turn to? Who was I going to tell? There was nobody that understands where I'm sitting because I don't know any other Pacific Islanders that have autistic children. I went and told my family and they just went and shrugged it off. So I didn't really have anyone to tell, anybody to talk to. Nobody would understand me.

I had different, different (pause) early intervention teachers, different speech language therapists, so I don't know who I'm dealing with and for me I think the frustration for me is repeating my story over and over again. ... you are thinking, "Well, don't you have all my notes?" I think from then on I had the barrier up – there was a barrier.

For me if I have somebody come to my door I think that's it and even if I don't like them I will say nothing; you know what I mean. ... Because ... if I voice my opinions or if I voice my concerns ... I thought oh I would have blown it and you might not come back and help my son. And so I'd sit there and say nothing.

Ofa's story underlines the challenges that families experience when they enquire about support for their children with special education needs. The initial shock that she faced when

her first son was diagnosed with autism, her family's reaction, and the number of professionals who are involved, all created many barriers for her. It took her a while to develop the confidence and knowledge to work with support services to meet her first child's needs, and there was some fear that if she voiced her concerns that the professionals might not continue to help her son.

Suggestions for Improvement in Services for Families

The second question discussed here related to how SE services could be improved to increase engagement with and satisfaction for Pasifika families, and the *talanoaga* drew from earlier discussion from the previous questions. Suggestions for improvement have been developed from two main aspects of the research, facilitated by directly asking the participants. First, the interviewers were given strong feedback about the barriers Pasifika families experience when engaging with SE services and how these could be mitigated; and secondly, the families and Pasifika professionals, who were very vocal in making suggestions for increasing Pasifika families' engagement and satisfaction with SE services, gave further direct suggestions about how the service could be improved. Key themes included improving professionals' cultural intelligence and sensitivity; for example, one Pasifika professional felt that, ideally, the first person to have contact with a Pasifika family should be from the same culture who could speak the same language as that family:

“I think just because I was born in New Zealand and I was brought up in this culture, so I understand a lot whereas if we had a couple with a child who just came from Samoa and a Pākehā telling them ‘Your child has special needs’, how would they accept it? They would find it hard to understand that you know; they will obviously get angry or why are you calling my child a handicap and they will interpret it in different ways” (Ian).

Non-Pasifika professionals, particularly those in smaller communities, need professional development in intercultural communication and sensitivity. However, while it is important to increase the numbers of Pasifika professionals, including support staff in SE, Pasifika professionals should not be restricted to working only with Pasifika families. One Pasifika professional strongly suggested this would lead to tokenism.

Lale and Moli also discussed the “slow start” in dealing with a health service where professionals made the assumption that they had self-diagnosed their children on the autism spectrum, and this created ongoing difficulties. Also, there was a concern that related to perceived cultural responsiveness in dealings with a particular staff member about their eldest son. The story they told was about the assessor who came from a different background: “An assumption [was made] that says he [their son] is slow and does not know what a gun is or ‘bang bang’ the sound a gun makes.” Their interpretation of this statement related to the more familiar context of visible weapons in the streets of the part of northern Europe where the assessor was from. In their own context, however, a child would not necessarily know what sound a gun makes. The lack of cultural intelligence and sensitivity in some professionals was a strong theme for many of the families.

Families made it very clear that poor relationships with professionals created a significant barrier to them engaging with SE services. Frequently the families complained that too many professionals were involved with their child and that there was a lack of communication and consistency between the professionals and between the professionals and the family. Where better communication happened (usually informally), families reported feeling more satisfied. When relationships were poor, families found themselves agreeing with the professionals

rather than asking questions or making their own needs known; for example, Aso said that she did not want to question the professional involved with her child. One way of reducing this would be to assign a key professional for each family who could take responsibility for building relationships between the family and service providers, and to communicate and interpret the advice from all professionals involved with the child. These relationships should ideally carry on through the transition to school.

Another theme was about developing holistic support services such as local family service centres (one-stop shops), and fostering playgroups and parent-led community support groups. One possibility for encouraging this is through supported playgroups that are welcoming for families with children with special educational needs. Family-led support groups also need encouragement and assistance so that they are able to support each other; for example, the Pasifika autism support group.

There is also a need to work holistically with families. It takes time and lots of *talanoa* to build relationships, not only with families but with community groups such as local churches. Some of the family stories were based on the families' traditional cultural values and beliefs. Some participants reflected on how difficult it is to create a shared understanding with their elders at home as the traditional Pasifika concept of 'disability' sometimes contradicts the Western view. Some of the more traditional beliefs identified were about different perspectives between Pacific Island- and New Zealand-born parents, understandings influenced by shame and stigma, and also religious beliefs about disability and special education needs.

Professional development for both early childhood and school teachers was seen as being needed to improve identification and referral of children to SE services. Pasifika professionals reported that both early childhood and school teachers sometimes lack the skills, knowledge and capacity for identifying and referring children to SE services; for example, as mentioned earlier, six families in the study were not engaged with SE services because their children's early childhood teachers had not advocated for referrals. Some families reported that they had not felt welcome when they approached educational settings with their child. Research conducted as case studies of early childhood centres in New Zealand (Purdue, Gordon-Burns, Rarere-Briggs, Stark, & Tumock, 2011) shows that despite legal requirements, some programmes and staff have exclusionary policies and that these are underpinned by their attitudes and beliefs around difference. It was also reported that sometimes lack of engagement with families relates to families being resistant to working with SE services, despite good intentions and persistence from professionals. Professional learning and development is therefore suggested for early childhood and school teachers to support inclusion. This could enhance their ability to identify and refer cases when appropriate, and foster inclusive practices and attitudes in their day-to-day activities.

"I believe that and agree that every childcare centre should [have professional development to be aware of her child's condition] so that they don't have to go through what I went through first time I took my child there ... I came home feeling really low" (Rima).

Conclusion

The findings from this research substantiate the significance of underpinning Pasifika research with the principles of *teu le va*; in particular, supporting collaborative relationships alongside Pasifika voices, issues and concerns. Assigning interviewers from the same ethnic group to approach families and engage in *talanoa* was very successful. Because of this

process, families were more than willing to share their stories. This authentic *talanoa* can result in opportunities for maximising delivery of services and policymaking.

“I believe that people should come forward in the sense that we are no longer in our little Tonga nation. We have to let go of the old ways of looking at things and the way we approach situations. Help is there for us so we need to all come forward. If we want the best for our children, we should be responsible as parents. So it is nothing to be embarrassed of or ashamed of, but it is something to raise because we are living in country where everybody is equal, we have rights” (Larry).

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