Understanding special education from the perspectives of Pasifika families

Report to the Ministry of Education

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UNDERSTANDING SPECIAL EDUCATION FROM THE PERSPECTIVES OF PASIFIKA FAMILIES

FINAL REPORT

SCHOOL OF EDUCATION

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Executive Summary

This research was conducted in New Zealand in 2012 as a contract research project funded by the Ministry of Education. This project arose from the *Pasifika Education Priorities: Using research to realise our vision for Pasifika learners* (Ministry of Education, 2012). 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* puts Pasifika learners, their parents, families and communities at the centre of all activities.

The research was qualitative and involved in depth interviews with eighteen Pasifika families with children of early childhood and primary school age who have special educational needs; both those engaged and those not engaged with SE services. Ten professionals, whose role involved 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 family and professionals’ interviews.

The aim was to identify the strengths of current service provision; barriers to accessing SE services for Pasifika; and the extent to which cultural perspectives on disability and SE and 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 changed to increase engagement and satisfaction for Pasifika families.

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. These methodologies included Teu le Va (Airini, Ana, Mila-Schaaf, Coxon, Mara & Sanga, 2010) and Talanoa (Vaioleti, 2003, 2006). In addition, lalaga (process of weaving a mat) (Mulitalo-Lauta, 2000) was used as a metaphor for the snowball sampling technique used in the project (Heckathorn, 1997; Noy, 2006). Lalaga was used for participant recruitment purposes as there was an identified challenge in making contact with families particularly those who do not currently access SE services.

Because Pasifika cultural identity is relational rather than individual, relationships were nurtured during the research. Teu le Va (Ana, 2010) and Talanoa Research Methodologies (Vaioleti, 2003, 2006) both acknowledge the paramount importance of building and maintaining good relationships between the researchers and participants. All families were interviewed by an interviewer from their own cultural background. Eight of the family interviews (44%) were conducted in a participant’s first language and all were given a koha towards the cost of their contribution to the research. The research took place within the South Auckland area and one small Central North Island city. However, the numbers of family participants was lower than anticipated in the Central North Island city, so it was not possible to explore differences between the two communities.
Summary of findings
A summary of key findings relating to each of the research questions are presented below followed by a list of recommendations based on the study findings.

**Question 1: What aspects of SE service provision are considered strengths by Pasifika parents and/or caregivers of service users?**
The majority of the families whose children were engaged with SE services expressed some satisfaction with the support received from the professionals. Some were satisfied with the outcomes of the support on their children’s learning and development.

A substantial number of families felt that early intervention support services were strengths of SE. Where support staff in centres and schools were skilful and built good relationships with a child and family, parents were very satisfied.

Some families reported that they valued the professionals who worked with them for their cultural understanding, passion and their willingness to extend knowledge and practice to offer a professional service.

Others felt that the professionals had developed good relationships with families which supported their children’s development and learning. Two families said that when they had a name for their child’s special education needs for example autism, this enabled them to gain more support from early childhood and school teachers rather than their child being labelled naughty.

**Question 2: What barriers exist to accessing SE services for Pasifika parents and/or caregivers of young people with special education needs?**
Two main types of barrier emerged for Pasifika families in accessing SE services. These were personal barriers and systemic issues.

Personal barriers included language and cultural barriers and families’ lack of knowledge of available SE services. A further sub theme emerged as economic barriers that included the lack of transportation and the cost of care for children with special education needs.

Systemic barriers included those within the 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 the SE services were focused primarily on the child whereas families might need counselling, and/or support to meet the additional costs of raising a child with special education needs for example. 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 that supported them, they might be withdrawn from that service. The professionals interviewed reported that both early childhood and school teachers sometimes lack the skills, knowledge and capacity for identifying and referring children to SE services. For six families in the study who were not engaged with SE services, the reason was that their 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.

**Question 3: To what extent do cultural perspectives on disability and SE affect engagement and satisfaction with SE services for Pasifika families?**
One of the cultural beliefs described by participants that affected their engagement and satisfaction with SE services included a belief that child rearing is the parents’/family’s responsibility and therefore help outside the family was not
normally sought. Another cultural belief expressed by some participants was that there is shame and stigma associated with having a child with special education needs.

The majority of parents reported that for their culture, having a child with a disability was seen as a punishment or even a curse for something that they had done. Both of these beliefs might prevent families from accessing help and support. These beliefs were reported more as belonging to the grandparents’ generation rather than the parents; however grandparents can be influential in encouraging or discouraging access to support, or their ability to provide direct support to parents themselves. This was not the same for all Pasifika cultures. A Tokelauan participant indicated a difference between Pacific Island and NZ born, suggesting that community awareness and visibility regarding difference and disability is more pronounced when families come to New Zealand. Some participants reflected on how difficult it is to discuss with their elders at home the meaning of the concept of ‘disability.’ Their traditional views can sometimes contradict the meaning of this concept in the New Zealand context.

**Question 4: To what extent does the low number of Pasifika SE professionals affect engagement and satisfaction with SE services for Pasifika families?**

The responses to this question were grouped into three main themes. These were the need for more Pasifika professionals to work with families; the need for representation of all Pasifika ethnicities; and having enough Pasifika professionals to support cultural understanding of other professionals.

Participants noted the importance of sensitivity in building relationships with Pasifika families and also in respecting their language. As a result of their language preference, families need Pasifika professionals who are responsive and able to reciprocate appropriately in their relationship with the families, particularly as their first point of contact.

**Question 5: How could SE services be changed to increase engagement and satisfaction with Pasifika families?**

Suggestions for improvement have been developed from two main aspects of the research. Firstly by considering the barriers Pasifika families experience when engaging with SE services that could be mitigated; secondly from direct suggestions for improvement made by the families and professionals. Participants were very vocal in making suggestions for increasing Pasifika families’ engagement and satisfaction with SE services.

Key themes included improving professionals’ cultural intelligence, developing holistic support services such as local family service centres (one stop shops), and fostering playgroups and parent led community support groups. There is 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. Professional development for both early childhood and school teachers was seen as being needed to improve identification and referral of children to SE services.

These recommendations are summarised below.
Recommendations

Five priorities to increase engagement and satisfaction of Pasifika families with SE services

1. Improve professional cultural intelligence and sensitivity
   a. Provide professional learning and development in intercultural communication and sensitivity for non Pasifika professionals
   b. Ideally ensure that the first person to contact a Pasifika family from SE services is from the same culture and speaks the same language

2. Work holistically with families
   a. For consistency, assign one key professional to support each family and facilitate communication between professionals
   b. Maintain relationships and services across the transition to school including the child’s support worker
   c. Proactively work with other services to meet the holistic needs of the family and where appropriate include the extended family in communication

3. Strengthen local community support services
   a. Work with other services to create local services or ‘one stop shops’ located in each community
   b. Encourage supported playgroups that are welcoming to Pasifika families with children with special educational needs
   c. Encourage family led support groups for Pasifika families that have children with special educational needs.
   d. Provide professional learning and development to church and community groups to increase understanding and engagement with SE services.

4. Provide professional learning and development opportunities for teachers (ECE and school)
   a. In identification and referral
   b. To foster inclusion and inclusive practices

5. Increase resources to support Pasifika families’ needs
   a. Increase support for children with special education needs across the transition to school
   b. Be more proactive in providing and disseminating information materials in a range of Pasifika languages within communities
   c. Develop and disseminate resources to help Pasifika families support their children’s learning and development

The findings from this research also substantiate the significance of underpinning Pasifika research with the three principles of Teu le va, in particular supporting collaborative relationships alongside Pasifika voices, issues and concerns. This authentic talanoaga can result in opportunities for maximizing delivery of services and policy making.
Introduction

Manukau Institute of Technology was contracted by the Ministry of Education in 2012 to conduct a qualitative research project that arose from the Pasifika Education Priorities: Using research to realise our vision for Pasifika learners (Ministry of Education, 2012). One of the priority questions identified in the document is ‘How can we better understand special education from the perspectives of Pasifika families’? The Ministry’s current priority for Pasifika research in education 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 within the Manukau area and one Central North Island city.

The overall approach to the research was qualitative in nature involving interviews with key professionals and the families of children with special educational needs. Some of the interviews were individual and several of the family interviews included extended family. Both families who were using SE services and those who were not were included as participants. It is from this background that the Ministry sought a more in depth qualitative perspective from research participants, particularly from the family perspective. Blended Pasifika methodologies which were highly inclusionary in their nature were used.

This report summarises the findings from the stories shared by professionals and families within these contexts. It is hoped it will provide some significant insights about Pasifika families’ experiences regarding SE services. It also makes recommendations to improve Pasifika families’ engagement and satisfaction with SE services.

Background

A summary of the rationale for this research follows along with a definition of some key terms that relate to the research question. Increasing engagement with the Ministry’s special education services, particularly Early Intervention services, is essential for improving outcomes for Pasifika young people with special education needs. The Pasifika Education Plan 2013-2017 has a target and actions focused on increasing the percentage of Pasifika learners with special education needs that access early intervention services. Professionals are increasingly likely to work with a diverse range of families, many of whose attitudes, beliefs, values, languages, and customs will be different from their own (Alliston, 2007).

The Pasifika Education Plan 2008-2012 (Ministry of Education, 2008) views the term Pasifika as a collective term that is used to refer to people of Pacific heritage or ancestry who have migrated or been born here in Aotearoa New Zealand. Pasifika people have multiple world views with diverse cultural identities and may be monolingual, bilingual or multilingual. Therefore, the term Pasifika is defined differently depending on which context it is used, but for this purpose we will use the Ministry of Education definition.

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 the understanding of inclusive education.
that we uphold for this project. This is a view that is fundamentally relationship driven, in collaboration with parents, families and communities.

The Specialist Service Standards prepared by the Ministry of Education (2006), requires the professional practice of specialists working with children and young people who have special education needs to reflect the principles of Te Tiriti o Waitangi. The SE Service Pathway: Poutama affirms the principles for practice that are outcome focused, have an ecological approach, are culturally affirming and support engaged families/whānau. Valued services are ones that are inclusive, holistic and wrap-around, strengths-based and collaborative and empowering.

**Objectives**

The purpose of the proposed research is to better understand SE from the perspectives of Pasifika families, in order to increase engagement and satisfaction with SE services provided by the Ministry.

**Main research question**

How can we better understand Special Education (SE) from the perspectives of Pasifika families in order to increase engagement and satisfaction with SE services provided by the Ministry?

**Sub questions**

- **Question 1:** What aspects of SE service provision are considered strengths by Pasifika parents and/or caregivers of service users?
- **Question 2:** What barriers exist to accessing SE services for Pasifika parents and/or caregivers of young people with special education needs?
- **Question 3:** To what extent do cultural perspectives on disability and SE affect engagement and satisfaction with SE services for Pasifika families?
- **Question 4:** To what extent does the low number of Pasifika SE professionals affect engagement and satisfaction with SE services for Pasifika families?
- **Question 5:** How could SE services be changed to increase engagement and satisfaction with Pasifika families?

The research focused on describing ‘the problem’ as well as identifying solutions to issues raised, and the strengths of current service provision that could be built on.

The key audiences for the findings of this research are the Minister of Education, national and regional office SE staff, and other policy audiences within the Ministry and across the public sector.
Methodology

Given that the majority of participants, including all family participants, were Pasifika, a blend of two different Pasifika research methodologies were used in this research project. These methodologies include Teu le Va (Airini et al., 2010) and Talanoa (Vaioleti, 2003, 2006). In addition, Lalaga (Mulitalo-Lauta, 2000) (a woven mat or the art of weaving) was used as a metaphor for the snowball sampling technique (Hekathorn, 1998). Lalaga was used for recruitment purposes as there was an identified challenge in making contact with families particularly those who do not currently access SE services (refer to Appendix A).

Because Pasifika cultural identity is relational rather than individual, relationships were nurtured during the research. Teu le Va (Airini et al., 2010) and Talanoa research methodologies (Vaioleti, 2003, 2006) both acknowledge the paramount importance of building and maintaining good relationships between the researchers and participants. As Helu-Thaman (cited in Coxon, 1997) argues, the cultural identities of most Oceanic people are relational rather than individualistic. These methodologies that focus on the importance of relationships highlight three principles that underpin this particular methodology for research. The first principle sustains the centrality of valuing relationships between all relational spaces among the stakeholders so that “collective and collaborative approach to research are valued and acted on” (Airini et al., 2010, p. 9). The second principle highlights that Pasifika voices, issues and concerns are maximized through strong research processes within these collaborative relationships, so new knowledge and understandings are formed. The third principle relates to this newfound knowledge and understandings, and is acted on through maximizing delivery of services and policy making.

These understandings involve “the centrality of valuing relationships and the need for Pasifika educational researchers and policy makers to acknowledge that the sacred and secular aspects of their relationships need to be ‘looked after’, valued and acted on by mutually empowering processes” (Airini et al., 2010, p. 12). In alignment with this philosophy, recruitment of Pasifika interviewers to work with a particular ethnic group enhanced that relationship as they bring with them the knowledge and understanding of how to respect that sacred and secular space between them and the participants. Not only that, they worked in collaboration with Pasifika families to ensure that the participants’ voices are acknowledged throughout the whole research. To further maintain that reciprocal relationship, the interviewees were given a koha or meaalofa in return for sharing their stories.

Talanoa (Vaioleti, 2006) means conversation and telling stories. This was used as the framework for collecting data. Participants were asked to tell their story of engagement and satisfaction with SE. While there was an interview schedule, this was seen as a series of prompts rather than a set of questions. The interviewers were trained to listen carefully to the stories they were told and to use the prompts as a springboard to encourage further conversations, if the stories did not cover a particular area of interest.

Research design

For recruitment purposes, we used the Lalaga technique to seek out those Pasifika families who were accessing and not accessing SE services in South Auckland and one central North Island city. The research team had strong links and relationships with the Pasifika community and therefore we started the conversations with Pasifika professionals in the area. We set up an Advisory Group of mainly Pasifika professionals in Counties Manukau and held three consultation meetings. The first meeting was to discuss and gain feedback on the research design, the second to discuss the next stage of the research process including the recruitment of families and the final one to disseminate and discuss the project findings. It was envisaged that using an Advisory Group would ensure that the research was appropriate for the
Pasifika community. The Advisory Group was helpful in identifying family and professional participants, including those who were ‘hard-to-find’. (Noy, 2008). Some Pasifika professionals referred one potential family and others referred two or more.

The Lalaga method is essentially social as it often relies on interpersonal relations and known contacts and friends which work to equalise issues of power, particularly in researching often marginalised groups. The researchers identified community based Pasifika professionals through existing relationships and networks and invited them to help the team to initiate relationships with Pasifika families with children with special education needs; both those who were engaged with SE services and those who were not.

Non engagement was defined as those families who under the Specialist Service Standards (2006) had children and young people who were not welcomed and empowered as partners in their relationships with specialists and specialist service providers. Based on this definition, we grouped the participants into two categories; those who were engaged and those who were not engaged. These categories are further defined in the participants’ section. The reasons for non engagement could be that they had no contact with the providers; that there was an initial approach made, but there was no follow up; or the child had been assessed, but the family chose not to access the services.

The weaving of a mat demonstrates the chain referral technique (see Appendix A). The Lalaga (snowballing technique) starts with two or three people (Noy, 2008) and then these people would refer more participants from their social networks.

The research was based in two locations; South Auckland and a central North Island city. The original rationale for this was to explore any differences in engagement and satisfaction between large and small communities. Although the research team had existing relationships with the Pasifika community in the central North Island city, the numbers of family participants was lower than anticipated. Therefore it was not possible to explore differences between the two communities.

Interviewers and existing relationships

Atkinson and Flint (2001) suggest that researchers “…require some previous knowledge of insiders in order to identify initial respondents” (p. 4). We employed seven interviewers from different Pacific ethnic groups to approach families within their own culture (Appendix B). This was based on the premise that by sharing the same culture, interviewers would have the knowledge and understanding of relational space or ‘va’ that in relationships must be adhered to when approaching families. Interview schedules, participant information sheets and consent forms were translated into the seven identified Pasifika languages. All family interviews were conducted by interviewers from the participant’s home culture and were conducted in the language of participants’ preference.

It was fundamental to employ these different ethnic interviewers as families tend to be willing to talanoa to those from the same cultural background. For example, one of the families when approached by the project coordinator to be interviewed refused to participate, but when they were approached by the interviewer from their own culture, they were willing to share their story.

Interviews for professionals were generally conducted in English by the project coordinator and another research associate. The interviewers from the seven ethnic groups recommended families to interview or were assigned families to interview if they were referred from other sources. Families were matched with interviewers from their own cultural background. The project coordinator trained the interviewers and sometimes co-interviewed families, which ensured quality.
Participants

Participants were recruited through the Lalaga approach. Family participants were more easily approached in the South Auckland context but family recruitment was more difficult in the central North Island. The challenge was that culturally appropriate procedures needed to be employed before conducting talanoa research effectively with participants. The importance of understanding cultural values and beliefs in the different contexts in which the research is located was paramount. This reflected what Atkinson and Flint (2001) argued that in order to identify the participants, researchers need to have an inside knowledge of the context in which research is done. If this cultural context knowledge is ignored, participants may end the talanoaga (conversation) early or refuse to share their stories (Vaioleti, 2006). However, in this research project, the researchers managed to avoid these possibilities by following culturally appropriate procedures including gaining approval to approach the families from the Tokelauan Council of Elders. We successfully identified families from seven Pasifika ethnic groups as shown in Figure 1 below.

Two parents also participated in a focus group to explore their suggestions for improving SE services. The ten professionals (figure 2 below), were from six cultural backgrounds including the only two European participants. Appendix B provides a summary of participants and the dates of their Talanoa (stories/interviews). Pseudonyms were used for the participants in reporting their talanoaga. The interviewers were all from Pasifika ethnic backgrounds. They also became participants when they participated in a focus group (Appendix B). They were asked to reflect about their experiences when they approached the families. However, the interviewers’ first names were used as this ensured ownership of their talanoaga.

Figure 1: Ethnicity of family participants (N=18)
We had a slow start in finding families to participate, particularly those families who were not already engaged in services. The pace of recruitment increased as the project progressed through the relationships that developed through the process. We continued to receive referrals, and ceased interviewing when there were no new insights, relationships, codes or categories emerging, ie, ‘saturation’ had been reached (Creswell, 2002; Vaioleti, 2006). This was confirmed when key insights from early interviews were also in subsequent interviews. This occurred when the coding that had already been completed adequately supported the emerging theory of Teu le Va.

Of the eighteen main family participants, eight were New Zealand born and ten were born in their home nations (Island born) (refer to Figure 3 below).

Eleven of the families had children who were engaged with special education and seven were not engaged (refer to Figure 4 below).

We defined those families whose children were not engaged as those who had no contact with SE, or those who had made an initial approach but had not been followed up and those who had been assessed but who had chosen not to access SE. Of the seven families, four were New Zealand born and three were Island born. Of this seven, three
identified themselves as Tongans, and one participant from each of these ethnicities: Samoan, Cook Island, Niuean and Tokelauan. All seven of these non engaged families had no contact with SE services, and we were unable to find families in the other two categories.

**Figure 4: Family engagement with special education (SE)**
Analysis

Data was coded in themes in reference to each research question in the data analysis stage. This was done collaboratively by the lead researchers. We then used the NVivo 9 software for coding sub questions into a broad range of nodes representing themes. We then expanded these sub themes into significant findings for each question by looking for ‘strong statements’, usually by greater numbers of agreed coded responses.

Reliability

The project coordinator met with the interviewers to cross check each family’s data transcription. Translations if necessary were done by the interviewers and the project coordinator who also was an interviewer.

Inter-rater reliability in coding was done by more than one lead researcher for eight out of a total of ten professionals’ interviews and for the majority of the family interviews. This was done by finding agreement (from our definition of each sub theme) for assigning a code with the other person or the team as required.

Data was coded again using the grounded theory approach (Charmaz, 2006; Strauss & Corbin, 1994) to understand how reality is socially constructed by participants. We used ‘axial coding’ to make links between the five main categories relating to our research questions and our codes. The essence of axial coding is the interconnectedness of categories (Creswell, 1998). Therefore codes were explored as well as examining their interrelationships and the codes and categories are compared to existing theory. This process built up our main themes backed up with participant responses that told the story, and we developed the themes in these five steps:

1. Coding respondent quotes under the five main research questions and developing sub-nodes from the stories
2. Highlighting quotes we might use (strong responses)
3. Combining nodes to develop themes
4. Choosing 2-3 quotes representative of each theme
5. Creating a brief summary of each theme

Each of the project team completed the data analysis for one question, except for Question 2 (barriers for families) that the Project Coordinator coded along with another research associate for reliability.
Findings

Talanoa provided us with in-depth data about the participants’ realities and aspirations. As Vaioleti (2003, 2006) argued, “it provides the cultural conditions that allow emotions and other authentic senses integral to Pacific” (p. 15). Further he suggested that Talanoa findings are authentic and trustworthy. However care is much needed in writing up of leo (spiritual essence of a person’s communication) and lea (words) as often written words do not contain the deep context, space, time and place that give meaning to the leo (part of one soul that is carried by spoken word or concept) (T. Vaioleti, talanoa, September 13, 2012).

The following section highlights the findings we found through the analysis process for each of the sub questions. We chose to foreground five family stories to strengthen the meaning of leo and lea in the talanoaga (conversations) and these are displayed as vignettes. The vignettes are edited versions of participant interviews which were used to tell the main points of their story in their own words. The main themes are summarised for each of the research questions and are supported by quotes from participants.

Strengths

What aspects of SE service provision are considered strengths by Pasifika parents and/or caregivers of service users?

The significant themes that emerge from the participants’ responses about the strengths of SE services include satisfaction with SE services and early intervention support services.

The majority of the families whose children were engaged with SE services disclosed some satisfaction with the support received from the professionals. Most stories demonstrated similar reasons why families were satisfied with the care and support that their children received. Some were satisfied with the outcomes of these supports to their children’s learning and development:

Well what really happened was that I didn’t really understand that he (son) needed that extra help and I’m glad that he’s getting help (Tasi)

A substantial number of sources also viewed early intervention support services as a strength to SE services. Other themes included cultural understanding of professionals; building on good professional practice; passion of the professionals; good relationships between professionals and families; and the importance for families of attaining a name or ‘label’ which helped them and others support the child. These themes will be discussed further after the vignette. Ian’s story demonstrates how one family appreciated the support that their daughter received from engagement with SE services.

Ian is a New Zealand born father and his story reflects a common theme of families who were satisfied with SE services and also the support they have received. Ian’s appreciation derives from the fact that his daughter was able to achieve new skills because of the support from the professionals.
Ian’s story (Talanoa, Ian, 7 August 2012)

When Jane was first diagnosed she was taken to the Super Clinic to have her ears checked and assessed whether she was deaf or not and the conclusion was that she was not deaf and it was just that she was selective of what she wanted to learn. It was a bit hard for her to put things together like sentences and words.

When she was at early childhood centre last year, they sent a person from MOE to sit with her and they designed a programme for her specifically to help her read properly. So they tackled the reading problem first, I mean that was what they recommended so twice a week they will have a person coming to (ECE centre) to help her to read, take her out of class and sit with her and spent an hour with her.

Just recently...what the speech therapist did was get her to say a sentence, write the words down and then the speech therapist cut up the paper and put it in front of Jane and let her put it back together for us at home. She did it together and I was happy as she was able to put it together from nothing.

I recommend it for other children that have the same problem as my daughter coz it is really helpful for her to come out of her shell. She is now talking and writing better now and drawing a lot of pictures.

That was a big jump for a year and a half.

If you could pass on my thanks for helping my daughter coz it would be impossible for me to stop work and really focus on her.

Cultural understanding of the professionals

One theme that both families and professionals reported as a strength was the ability of some professionals to understand different cultural protocols and to be culturally responsive in working appropriately with families. The development of inter-cultural communication skills of professionals is vital to grow their practice:

...they actually – I think they are really genuine in their desire to work with Pasifika families – with Pasifika communities. They just want to know – they are just wanting some guidance and some support (Greg, Pasifika professional).

I found well there was an early intervention teacher, she was Maori and she understood. I don’t know if it was the cultural – she understood everything that I – she went above and beyond her job if you like. (Ofa)

Professionals using Pacific languages

Both professionals and especially families highlighted the crucial part that language plays in families’ engagement with professionals working with them. Some reflected that they had been engaging in positive relationships with the professionals who understand and speak their own language whereas some families did not have access to a Pasifika professional. One family reflected that:

Yes, I think there should be a Pasifika professional who understand my language so I could ask that person questions. Vavega also needs a Pasifika person who speaks the same language so we could ask those questions (Aso).

No participant, either professionals or families, specifically commented that they have had the experience of working directly in their home Pasifika language. For example, Jacinta (Pasifika professional) reflected that sometimes they had
to use interpreters to help families understand. However, some commented about how Pasifika families appreciated working with Pasifika professionals.

**Professional knowledge and fostering good relationships with families**

Another theme that was highlighted in the responses was the ability of the professionals to continue building good practice in their engagement with the families. The following comments relate to staff in general who were interested in improving their practice and being culturally responsive, as well as having support workers who are knowledgeable about working with specific needs, for example autism, in a reciprocal and responsive manner. Support workers and their capabilities were mentioned many times by families as making a huge difference in satisfaction:

...so it’s not about getting rid of whatever they were doing, it’s just building whatever goodness that – that they’ve already got in place because they are doing that already, you know -some families working effectively and engaging wider families. So there is a lot of good practice that is happening you know (Greg, Pasifika professional).

One of the strengths identified by participants was the significance of building effective relationships between the families and professionals in order to provide effective support for children with special education needs. This is reflected in one family’s comments:

Oh, the Group Special Ed team they were really, really good. Siaosi went to a really good preschool where they had a teacher aide who was used to autism. So she made it a personal goal to discover a lot of things that Siaosi liked, and from preschool they’ve found out he liked penguins and Toy Story, so they used that to help him with his learning... (Moli and Lale)

**Acquiring a ‘label’**

One of the themes that was reflected in some of the participants’ responses highlighted the importance to the family of sometimes attaining a ‘label’ or perhaps a medical diagnosis of a specific disability or need. Through the support SE services provides, it is also a way for families to engage with teachers in meeting their child’s needs. As one family shared:

You know if I didn’t have that label – I would have struggled through the education system trying to find like you know teachers – well I battle with teachers anyway saying why is my son naughty? Or why is he behaving – why is he throwing tantrums? But now with that label there, they are more – they are more sympathetic and empathetic and also I can educate them around you know… (Ofa)

This comment shows not only the struggles that families have sometimes in accessing support, but also that having a special education need that is more visible to others may enable a child in some instances to have better access to services. Labelling is seen by some as a barrier as it can be used to exclude children from accessing services, but some families felt it helped them to access support:

Yeah, we have an amazing case at the moment with a student that’s got hearing disabilities that was picked up early, and so we’ve got the professional, the special ed. professional that’s working so brilliantly with us to transition the child into a normal classroom with the hearing aids and getting over those fears and stuff like that (Lola, Pasifika professional).
Barriers

What barriers exist to accessing SE services for Pasifika parents and/or caregivers of young people with special education needs?

There are two key themes identified as barriers for Pasifika families in accessing SE services. The barriers identified are personal barriers and systemic issues. Personal barriers include language barriers and economic barriers. Families’ lack awareness of services can also be a barrier as well as sometimes a family’s resistance to working with services. An additional personal barrier is the families’ situation. The examples of economic barriers that came up from our talanoa include lack of transportation, living a long way from services and the additional cost of care for children with special education needs. The majority of these economic barriers are beyond families’ control. For example being a solo parent and only one person working because of the need to care for a child with a special need.

Systemic barriers incorporate both those within the SE services and in the broader sense of services for families with special education needs in general. For example, some families reported poor relationships between services and families as well as lack of cultural intelligence and sensitivity in the clinical behaviour of professionals.

Although most families shared these barriers as a limitation to engagement with SE services, the following two feature stories highlight 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.

Both Ofa and Gase shared the difficulties that they had to experience in accessing the services.
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 because I was trying to get over the emotion. And from there they yeah 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 the support for their children with special education needs. The initial shock that she faced when her first son was diagnosed with autism along with her family’s reaction created many barriers for her, including the number of professionals that are involved. 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.
Gase whose story is told next, is a New Zealand born Niuean with four children, including a six year old daughter Tara who has special education needs. All four children were born in New Zealand and live at home with Gase and her Niuean husband, Frank. Gase talks about the lack of support she received as a parent of a child with special education needs such as for transport, counselling and also the frustration she felt when SE funding was withdrawn as Tara started school.

Gase’s story (Talanoa, Gase, 5 August, 2012)

Tara was born [at] 28 weeks - premature. She developed ... slower than children when she reached ECE age, but she also was diagnosed with ‘Scoliosis’ which was a build up of cerebral fluid in her spine which damaged a lot of the nerves relating to her arms, her fingers, movement and also her legs and her feet so she needed a lot of aid as well. She was very clumsy when she was standing, running, so that was the purpose of her, us having to look for someone to aid her there, especially toileting.

[Tara] ... spent a lot of time in hospital... maybe most her life since she was born. She was so tiny and a lot of people compared her to other children...because she couldn’t pick something up you know and because ... she walked funny.

My Mum ... was always there ... because we had our other children, she was always there taking her like at hospital, bringing food, moral support. She was always there for Tara as well, stroking her, touching her, just voice recognition as well and also helping my husband – there was transport as well that she...yeah I’d have to say my Mum did a lot.

[They could have offered] pastoral care, or support. ... There was a time where we were told that Tara may not survive; they didn’t offer us ... a counsellor to come in, nothing like that. We weren’t offered any transportation, help or support. Coming from Auckland Hospital to Mangere you have to imagine that’s quite a lot of petrol being used. And it was only one of us working ...

The help [Tara] got in respect to her individually was she had occupational therapists, she had special language therapists, she had a physio therapist as well and I think all of them they, they played their part.

[Tara] doesn’t have any [special educational help now she is at school]. They only funded her, I think it was only for 2 weeks and then after that, you know, Tara didn’t qualify. I think because she started developing a little bit of independence by that stage. She was toilet trained. She still wore pulls ups every now and then to school, She was starting to write. That was all thanks to N, [the teacher aide]. I think they could’ve funded Tara for her to have a teacher aide or support person there with her, for awhile. Because she was familiar with N..., she wasn’t familiar with anyone else, but they, they took that familiarity away from her and left her with someone she didn’t know and then they struggled because she wouldn’t talk to anybody, so I think if they had you know at least allowed for her to have a bit more support, yeah, we didn’t ask for full time, but you know maybe a couple of days a week or you know, where someone could come in and aid her with things that she needed just for support.

Gase’s story illustrates similar barriers to Ofa. The challenges that she has had to face prevented her from engaging fully with the support services. The family’s expectation of receiving pastoral and financial support during the time of need was not fulfilled. This resulted in emotional consequences that the family had to overcome. The gap in support
between the early childhood centre and the school was particularly difficult for this child and family. Not only was there no continuity in the support worker, but also the funded period for the child when she enrolled in school was short.

**Personal barriers**

**Language**
The majority of participants viewed language as a challenge in engagement with SE services. This is both the professional language used as well as the use of English. As a consequence, families do not understand and therefore just agreed with what the professionals said. The quotes below demonstrate this and other barriers that limit families’ engagement with special education:

*I don’t understand the words and (Peli) and Rose explains to me in the language – the hard language they, they explain to me what it means and I am slowly learning the English. I just need to have more people like Rose and (Peli) to help me and my family understand what we need to support Sasa.* (Tasi)

*…we are constantly working with these, these professionals, that want to do assessments, that know what should happen and stuff like that, but have no cultural relationship translation for it all. And so we often find we are doing a lot of that, not, not literal translation into Samoan, but translating it…* (Lola, Pasifika professional)

**Families’ lack of awareness and understanding of services**
Families’ lack of awareness and understanding of services is another personal barrier. Sometimes if families are not yet involved in the ‘education system’, they are not aware of the supports available for the child and family. There is also a reluctance to self refer:

*There is a lot of – there is a lot of work that needs to be done amongst our Pasifika families, especially with children – there are a lot of children in need and that we actually don’t know of. They are in the community, but I think the lack of understanding that they can come forward and ask for help – they don’t know where to go – they don’t know who to talk to…* (Foa, Pasifika professional)

While families may experience barriers because of their lack of understanding, sometimes this problem arises because the professionals do not clarify their roles sufficiently:

*Well, not too bad. I still felt I did not know enough like I did not know Siaosi has speech therapist that there were two people working alongside him. I did not know what the speech therapist, what the person was supposed to do and I asked them; “What do you guys do?” I don’t think they clearly define their roles I was just thinking that they were helping us when they referred Siaosi (Moli and Lale).*

*I do not know what the people from these services are doing with Kia except the man who comes to the house (Teine).*

One professional discussed a local family who was resistant to working with SE services. The example below discusses the barriers to engagement that families can experience, and how frustrating this was for the professionals who wanted to work with them:

*…they weren’t able to access it – they had a lot of input from the services – from numerous services because their child had multiple needs. But they just wouldn’t commit. They wouldn’t turn up to meetings, they wouldn’t go to appointments and that was so frustrating because this child was making*
huge leaps you know and he hadn’t had a support worker for ages he was one of those children. And the staff had worked diligently with the child and saw such amazing things happen and it was so frustrating when you know some of the team would make appointments to come into the centre so Mum didn’t have to go to 3 different places and she just wouldn’t turn up (Tina, professional).

**Economic barriers**

The additional expenses for families to be engaged with services are sometimes a barrier. This was reflected in some of the participants’ responses. This can include having no transport as in Gase’s situation:

> The financial side is extra burden because we also have to provide extra things for her. Not only that in term of the government, nothing has been offered in the sense especially in resources for schooling and as she’s growing, the expenses raise. It becomes more and more (Larry).

One of families suggested that the Pasifika community needs to come together and advocate for more funding from the Ministry of Education:

> I need ah I think for me right now they need the funding more, but in order to get the funding we need to come together as community and bring that on board to the Ministry of Education (Rima).

These financial issues can sometimes become a burden to families and limits their engagement and satisfaction with services.

**Systemic barriers**

Sometimes agencies seem under pressure from overwhelming work and the professionals have high caseloads. This can interfere with relationship building which is so important for working with Pacific peoples. The systemic barriers identified were: the need for wider support for parents, families and communities, poor engagement with families, lack of cultural intelligence and sensitivity, and different responses to community needs. A few participants also noted issues associated with family transience.

**Wider support needed for families**

Moli and Lale’s family noticed the difference in services when they moved to Auckland. Moli wanted to support her son but was not given help to do so:

> I did not know what to ask like are we supposed to have things at home to do. That was a bit tricky. Like with Fritz he had [speech] exercises every week to do and we and the boys practiced together but when we were at[our new residence], they did not give us the support tools (Moli).

Some parents like Moli and Lale needed more direct advice as to how to help support their child at home. Sometimes the need for support services for families goes beyond only educational support for their child with special education needs:

> Sometimes I feel that me and my husband need to get some sort of support – more support. At the moment special education is only focusing on Sasa. But me and my husband and my family need to understand what happened to him..., and not to be judged because we live in a small house with a lot of children and that’s what I feel. I feel that I’ve been judged because of the amount of children I have [including a child with special needs]. I’m not working, I can’t get in the extra help and yeah, I just feel that me and my husband need some sort of support so that we can help Sasa (Tasi).
Working holistically with families in a proactive manner can help to meet other needs. This could ensure the whole family’s involvement and the service providers may then better understand ways to support them, and therefore limits their feelings of being judged.

**Poor engagement with parents, families and communities**

Some families, for example Ofa’s, and also professionals found that the large numbers of staff in services working with the family sometimes overwhelmed them. As a consequence, families do not understand what is happening for the child:

> We’ve got a situation where we have got three, three clinical psychologists working with one, one person and they talk past each other and one person comes in and undoes what their doing. (Lola, Pasifika professional)

> All these strange professionals are going to come in. Because you know the thing is with Group Special Education, the service is they go into the home as well as into the centre so you know that’s a big expectation for parents feeling oh gosh, you know the psychologist is coming, the speech language therapist is coming, the itinerant teacher is coming, oh you know how will they think about our home you know those sort of things and they talk to teachers about those things you know they are coming to a home visit. (Mareta, Pasifika professional)

> I was really scared because I wasn’t sure how it was going to happen or what the tube looked like. It just felt really scared. I just went along with it. I didn’t ask any questions or...yeah (Avery).

**Lack of cultural intelligence and sensitivity**

Sometimes the professionals’ lack of understanding of cultural norms or being aware of ways to communicate interculturally creates barriers for families. Also, there are professionals who simply make judgements about a family from the beginning as far as their ability to understand the process and their child’s needs:

> …their needs are more important than just the paper work for special [education] needs – you know it could be spiritual…it could be our spiritual needs [also should] be acknowledged and our emotional side too (Sefina, Interviewers focus group).

Lale and Moli also discussed the ‘slow start’ in dealing with a health service where professionals made the assumption that they self diagnosed their children on the autism spectrum, and this created ongoing difficulties. Also, there was a particular 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 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, 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.
Different responses to meeting community needs

Some respondents thought that teachers may also tend to accept difficult behaviour as ‘normal’ in contexts where there are many children with varied needs. This could be due to sometimes not being proactive because of various factors including the level of need in their centre/school, and only the highest potential SE needs might be referred for services. In other communities, for example schools in higher socio-economic areas those behaviours could be seen as grounds for an immediate referral, resulting in an overall higher number of referrals in these areas. This might also be influenced by lack of engagement with families:

  ...one of the conclusions that I have drawn ...is that people normalise certain behaviour [in] low – socio economic schools, A school who’s not used to that sort of behaviour will see it as naughty or [inappropriate], and then they quite likely will refer. Over here they see 50 or 60 [of children with these needs] so it’s like they will be alright, you know [without being referred]. (Greg, Pasifika professional)

For one parent this barrier relates to equity issues:

  ... because for us in the lower socio economic ladder, we are dealt with [in a] different manner from people like in [a higher socio-economic suburb] or higher parts where economically they earn more. The ethics that happen to us as we are also viewed as ‘second class citizens’ and I believe that should not exist in our country in New Zealand (Larry).
Cultural perspectives on disability
To what extent do cultural perspectives on disability and SE affect engagement and satisfaction with SE services for Pasifika families?
Some of the beliefs identified by the participants for this question include: child rearing is a parents’ job; different perspectives between island and NZ born; talanoaga from their own personal view from their Island group; understandings influenced by shame and stigma, and also religious beliefs about disability and special education needs. Some of the stories are based on families’ traditional cultural values and beliefs. Some participants reflected on how difficult it is to create a shared understanding with their elders at home in regards to the concept of ‘disability’ that sometimes contradicts the western view. Larry’s story outlines some of these issues in regards to traditional cultural perspectives on disability.

Larry’s story (Talanoa, Larry, 14 September 2012)

Larry was born in Australia but he is from a Tongan background. His daughter Jolly was also born in Australia but is a New Zealand citizen.

Why they hide it? Yeah I think people hide it because of embarrassment because in terms of Tonga belief when something happens to a child it is usually seen as a fault of parents or grandparents or descendants from earlier. We often view it and we look at each other as a person has been guilty of something. And because of our Christian faith, it can also lead to people interpreting it as a curse upon a family which brings a shame upon our small island community in our thinking and also the way we look at things.

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.

I suggested they would let people such as me to know it earlier. I believe they could have approached me a lot earlier since my daughter has been in preschool. Better communication is needed between the Education and Health [services] so they know the needs of the children with disabilities and also [understanding] emotional [needs] which creates emotional [difficulties]and other factors that could have an impact on their lives and families.

Larry’s story depicts changing views in regards to disability and disability services from a perspective of a non Tongan born father. He suggested that families need to advocate for their children with special education needs by overcoming the barriers related to stigma. Other themes raised in the talanoaga are related to the following areas.
Understanding special education from the perspectives of Pasifika families

Child rearing is a parents'/family's job
A few participants stated that child rearing is a parent’s job from their traditional perspective of child rearing practices:

Yeah, an issue I think our families have, and why they are not accessing early childhood services is that child rearing is seen as the parents’ job ...but my mother in law just wouldn’t...she found it hard to give them up for someone else to look after (Kina, Pasifika professional).

We’ve got one [child with special needs] in the family and...we always keep him at home. We don’t want to take him to school, we just keep him – we think that we are the ones who are the best to look after them, but here [New Zealand] there are special people that are better than us (Ana, Interviewers focus group).

Differences between Island and New Zealand born
Some participants shared their views on how disability is perceived between the Pacific Islands and New Zealand born parents. New Zealand born families experience fewer language barriers and better knowledge of systems in relation to understanding services:

...the obvious thing according to difference in the ability to is the understanding because if you are talking about NZ born they will be educated here so a lot of the language stuff you can articulate to them quite well (Greg, Pasifika professional).

I think just because I was born in NZ 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).

There is also some indication that the community awareness and visibility regarding difference and disability is more pronounced when families come to New Zealand:

It’s interesting you say that because you know that word autism (pause) and I suppose working with any condition – back in the islands – back in Tokelau they are not treated any differently. It’s certainly not an issue in...there is a shame involved here in NZ, but as I explained before in Tokelau there is nothing. They’re just a part of the community and it’s not until you come to NZ that you know those things are more pronounced...you are more aware of it and there is a shame (Kina, Pasifika professional).

I think Niueans have a smaller population too. There are children that have had special needs, but they are all grown up and they fumbled their way through life, whereas because obviously it hasn’t been that well promoted. Otherwise our young ones that we interviewed would have been quite clued about things - instead of not knowing. But, yeah to look for these children is almost using the Pacific Island network of coconut wireless (Charlotte, Interviewer focus group).
Shame and stigma

The cultural barriers that limit the participation of Pasifika children with special education needs to be included in the community often relate to traditional views of shame that can stigmatize families. Most participants discussed how this was experienced or became evident for them. The Māori term ‘whakamā’ means to feel shy, embarrassed or has a loss of mana. Several participants used this term to describe how families feel:

...some elements of what I’m seeing now in my role is that when we are talking special education...children with special needs, those are the things that Pacific parents I suppose and Pacific communities are not used to. And I think that there’s a certain level of whakamā, you know that they are quite embarrassed (Greg, Pasifika professional).

I think understanding my culture – where I come from in the Cook Islands. We are a bit ashamed, to know that Sasa needed this help and was to me – well he’s 5 years old now and I didn’t realise that he needed that help. He started at the Playgroup at 4 and they just realised it now and I’m still trying to understand what’s wrong with him and my husband doesn’t think there is anything wrong with him, but I’m just happy that he’s getting the help and yeah – maybe someone that understands my culture that you know we, we whakamā – you know shame (Tasi).

They may want to learn and I know through the Pasifika families that I have met...a lot of them it is embarrassment. They don’t want to take their child so that people look at their child differently (Greg, Pasifika professional).

Yeah and especially all the...old people, they look at ...and always bring with them that belief that they don’t want to talk about it because it might be a curse for a family (Rima).

Like whakamā – shyness, shameful. All negative stuff. You know like – I don’t want any people to know about my problem. We don’t have – normally we don’t have the confidence [to share it] (Ivy).
Low numbers of Pasifika SE professionals
To what extent does the low number of Pasifika SE professionals affect engagement and satisfaction with SE services for Pasifika families?

One Pasifika professional who works with children with special education needs at a hospital reflected that Pasifika children are able to make connections when they see a ‘brown face’ walking in the play room. Children tend to interact mostly with the Pasifika person instead of a palagi. This provides a rationale to increase the number of Pasifika professionals:

*I don’t want to seem naive in saying that sometimes some of our Pasifika families do not want to speak to a Palagi or you know – so when I walk into the room to introduce myself it’s like oh there’s another brown face and the connection begins* (Jacinta, Pasifika professional).

The responses to this question covered three main themes. The main issue is about a lack of Pasifika professionals to work with families, as is discussed below:

*I find that if you do have teachers of Pacific Island ethnicity it does make a difference in terms of language with bonding, you know with some families and it’s also support for the teaching team for the other members because it’s a strength and I think that we don’t have enough Pacific Island teachers. I would love to have a lot more Pacific Island teachers for our Pacific Island families within our organisation.* (Mareta, Pasifika professional)

Secondly, there is a need for representation of all ethnicities in the various Pacific Island cultures, sometimes because of the need for speakers of the same language, but also initially at least to connect and build good relationships:

*Yes, I think there should be a Pasifika professional who understands my language so I can ask that person questions. Vao also needs a Pasifika person who speaks the same language so that we could ask those questions.* (Aso)

*…first be grounded and have a good understanding of individual Pasifika culture and unfortunately there is no way around it. You’ve got to have the right Pasifika people, you know: Niuean to Niuean; Tongan to Tongan to bridge that.* (Greg, Pasifika professional)

Thirdly, there also needs to be enough culturally competent people to support cultural understanding of other professionals:

*…[building that relationship] takes time. You grow those relationships – because I have got some really brilliant – you know Pākehā/Palangi colleagues…they do really well and they connect…the difficulty will always be when we have conversations with them is that the language – those connections sometimes are not quite as good as it should be.* (Greg, Pasifika professional)

The previous quotes highlight the importance of developing inter-cultural communication skills with families and initially using families’ languages to increase their engagement with SE services.
Improvements
How could SE services be changed to increase engagement and satisfaction with Pasifika families?

The respondents were very vocal in making suggestions for increasing Pasifika families’ engagement and satisfaction with SE services. Suggestions for improvement have been developed from two main aspects of the research. Firstly by considering the barriers Pasifika families experience when engaging with SE services could be improved; secondly from direct suggestions for improvement made by the families and professionals. Both aspects have been amalgamated here.

Key themes are building better relationships between professionals and families, including improving professional’s cultural intelligence; developing support services such as local family service centres (one stop shops); and the importance of playgroups and parent led community support groups. There is also a need to work holistically with families, and that takes time and lots of talanoa to build those complex relationships. This relationship building should include working with local churches.

Rima’s story reflects common themes across the families’ interviews which were about the importance of early intervention services and working with teachers to foster inclusive education settings, as well as education in general for Pasifika families who have children with special education needs. This is more important particularly to those who have recently migrated to New Zealand.

For Rima, being new to SE services in New Zealand, she found that the connections and relationship she developed with the speech language therapist and early intervention teacher were very valuable. However, her expectation was that all ECE teachers would have a good understanding and the skills to support Raymond, which was not the case in the first centre he was enrolled in.

This experience and the practical issue of lack of transport for Raymond to attend this first Samoan centre meant that seven weeks after her interview, he was on the waiting list to attend a centre where there are other children with special education needs enrolled and which was also closer to home. The speech language therapist was very supportive in assisting with this move, but as the parents recognised the value of early intervention, and the wait time for assessments to access services became an additional barrier. Rima’s experience highlights the importance of building a relationship first between professionals and families, and to match support to family expectations. Also, families can sometimes need interim strategies to work with their child at home while they wait to access ECE centres. Rima also discussed the importance of working through communities, especially through extended families and family support groups to meet their needs. The following additional themes from the other participants added to the discussion about ways to increase engagement and satisfaction with SE services.
Rima’s story (Talanoa, Rima, 27 July & 17 September 2012)

Rima was born in Samoa and Raymond, her child with special education needs was born in New Zealand. Their story is told in Rima’s own words from her interview with the project coordinator in July and also a follow up focus group interview with 2 parents on 17 September.

The only people, so far that’s involved that I’m really happy about to know that Raymond’s getting that special care is the special speech therapist and an early intervention teacher.

... and also I think from [...] Trust they’ve given me ten days where, you know, we can use that. My family and I can go out, time out and pay someone to come in and help to look after Raymond. Or if I take Raymond to the doctors they can look after my other children, or when my husband and I need time out. So that’s what makes me, you know, happy to know that there is help and care and assistance for us through this very, you know, challenging time.

...taking Raymond to a Samoan [ECE centre] it’s new to [the teachers] and the first day they weren’t sure how to handle it or you know they don’t have enough information. They’ve never had the experience ....

I believe that and agree that every childcare centre should [have professional development to be aware of this condition] so that they don’t have to go through what I went through first time I took my child there you know. I came home feeling really low.

And it helps for our older generation, you know my grandparents and my – our parents to have the Pasifika language you know spoken to them in the way that they can understand because everything is in English and it’s hard for us to explain it to our parents...language is a big barrier and is sort of – I don’t know what we’re dealing with my son. We try and explain it to our parents and grandparents, but they don’t understand.

...but it does matter to me that our Pacific people understand this, you know ...a child with a disability condition – they need to be aware of [them] and how to help them along.

I think for me right now they need the funding more, but in order to get the funding we need to come together as community and bring that [on board] to the Ministry of Education.

And I do stress the Ministry [needs] to help us out in the resources and the funding for us, and you know for us to come out and to step out instead of waiting till it’s, you know it’s late.

Build relationships with the Pasifika community, early childhood centres and schools

Many respondents, particularly the professionals, said that it is important to build relationships with Pasifika before you can discuss a topic. The participants stressed the importance of working in collaborative relationships and a few suggestions on how to build those relationships. However, some participants reflected on some consequences if those relationships are not created. For example, Ofa reflected on one incident where a professional visited her child and she was reluctant to ask her to take her shoes off. Services need to be proactive in building these relationships. Building relationships with the Pasifika community needs to take place in the spaces where Pasifika people congregate, particularly the churches, or as another respondent suggested through Pasifika radio stations. Further ideas on how to improve relationships are discussed in the suggestions below:
... it’s about developing that relationship first ... They’re not going to come to a meeting if they don’t know who you are and what you’re here for. ... it’s getting to that stage where our people are – are comfortable in engaging (Kina, Pasifika professional).

One of the interviewers talked about growing up in a small Tokelauan community located in a central North Island city. There was a family that had a child with special education needs that she regularly met at church and in the community. She felt the child wasn’t treated any differently, but what really helped the family was being able to congregate together as a community:

*We had our own Tokelauan Hall. We also had separate churches - a Tokelauan Catholic group, a Tokelauan Presbyterian group and a Tokelauan /Samoan Baptist group.... it was such a strong community, regardless of our religion we were able to come together for fundraisers, sports games, and or socials events on a weekly basis. Families would bring their children, including any child with special needs, a child with special needs was treated like any other Tokelauan child, all children were treated the same* (Sefina, Interviewers focus group).

**Strengthen supported playgroups**

Two professionals discussed the importance of playgroups to empower parents to connect with other agencies, including SE services. Supported playgroups in particular have regular support from a Kaimanaaki or a Playgroup Educator that enables higher levels of parent engagement, curriculum delivery and home language and culture provision as a contribution to children’s learning outcomes and transition to school (Ministry of Pacific Island Affairs, 2012). Familiarisation with early childhood education and providing opportunities to make connections with other Pasifika families are important for Pasifika families:

...So we had a - what happened was so the women – the elder women did their bit and on one side we had the playgroup. P. was our coordinator. She was a Pasifika woman as well and that is how it really started because we were really involved in Pasifika things (Ivy).

**Increase awareness within the Pasifika community**

Some suggestions from the participants discussed the need for education about disability and SE services that may reduce the perceived stigma of having a child with special educational needs. Influencing Pasifika can often mean working through respected people or community leaders in the community such as ministers. This may be especially important in communities with small numbers of Pasifika where SE services could proactively build relationships with community groups, for example churches, who may have considerable influence with families:

... through the places that they most congregate and through people that in the cultural lens hold status, so whether that’s the minister, whether its the family, ... whatever it is, its often those people can often influence whole congregations of people (Lola, Pasifika professional ).

**Provide one stop shop, multi agency support services in communities**

A one stop shop approach would enable wraparound services for families and perhaps mitigate the economic barriers families face in accessing services. This would also encourage inter agency collaboration:

*Where everyone can come to and you’ve got all the cultures there as well – rather than there’s a service here – there’s a service there. Somewhere...because sometimes people don’t want to disclose what’s wrong with them you know they don’t really want to go there, but you need to build trust where they can come to a place where they can be really themselves and able to tell you exactly what their needs* (Foa, Pasifika professional).
One comment from a school principal related to the visibility of Pasifika service providers who were not actively developing relationships with schools. While she felt her school was very proactive in developing relationships, if the community professionals do not make themselves known, it is hard to know who to contact and what services are being offered:

*When you have to outsource the family wraparound stuff ...It's very, it's not visible those Pacific island providers, like who they are they, who is out there, ... other places will drop in and make contact with all these schools, the community constable, the health nurse, the, the local counselling services, they'll want, they'll want to make themselves available to you and your families. You don’t see that.* (Lola, Pasifika professional)

**Ensure that families are fully informed**

Further work to educate and inform parents and families about what is happening at each stage of their journey is important, as well as providing them with explanations, tools, strategies and resources. Also, ensuring that special education is communicated and explained using plain language, as well as information being translated into Pasifika languages is important. Education for families about disability awareness is also vital. This quote shows that parental attitudes that are open to difference are important for fostering inclusion:

*I just think with us Pacific Islanders; I think we need to be more aware and more open to the different special needs that are around us at the moment. Just be open minded, I think and just stand back and think when we see children of our own children like they’re all different...and I think having a special needs child has opened our eyes to, to different things which ...I gratefully appreciate that because if I didn’t have him we would be naïve or just hidden away from it.* (Olepa)

**Meeting families’ cultural needs**

Increasing the number of Pasifika professionals in SE services should strengthen the cultural intelligence and sensitivity within the SE services. This would enhance the cultural and collegial learning of its health and education professionals. Also having interpreters available is important for Pasifika professionals as well as families. Education in cultural competence for non Pasifika professionals is important in meeting families’ cultural needs:

*I’d hate to see professionals working with Pasifika solely as the work of Pasifika workers. ... it’s providing [non Pasifika professionals] with some tools they can use when they deal with Pasifika families so that it doesn’t just become my work – it’s their work - and they need to be at a standard where they are competent – you know they are culturally safe, but also have that cultural intelligence* (Kina, Pasifika professional).

**Initiate and support community support groups**

Initiate and support especially parent led support groups for families whose children have special education needs as sometimes parents feel isolated and need support to connect with other families to get help. Ofa was an active member of a parent led support group:

*where I started to get all the Pacific Island families you know just like from word of mouth and from our churches that like you know I’m telling my stories about how my – how I’ve got children with special needs and then they wanted to come and ask me. Yeah, it was from that word of mouth and then allowing to bring those other families that I had networked with – put them in and now they’ve got – they’re on Face book so you know I just – I’m just like the middle link. I just take them over you know* (Ofa).
Discussion

Introduction
The overall research question is about how we can better understand special education from the perspectives of Pasifika families in order to increase engagement and satisfaction with SE services provided by the Ministry of Education. Key findings from the research were used to develop recommendations to improve engagement and satisfaction. Five priority areas were identified for improvement.

Reflection on the research process
On reflection, the cultural approaches that were employed to seek suitable participants were very effective in this research. Lalaga was instrumental in meeting our goals, especially in finding the non engaged families in SE services. Atkinson and Flint (2001) argued that the main value of snowballing method is to obtain participants less represented or those who are in a context that requires a degree of trust to initiate referrals. This research was underpinned by the principles of Teu le va, and building relationships between the researchers and interviewers, interviewers and families, and researchers with policy makers were optimal and paramount. This ‘va’ between the interviewers and families was critical in the process of this research. Assigning interviewers from the same ethnic group to approach families and engage in Talanoa was very successful. Because of this process, families were very prepared to share their stories except one which turned us down.

Talanoa as a method of research incorporates the sharing of stories between the interviewers and families. This method was chosen because of its “…flexibility and open[ness] to adaptation and compromise” (Vaioleti, 2006, p. 25). Through sharing these stories we found that one of the reasons why children were not engaged with SE services was due to a lack of shared of understanding about the process of referrals. For example, one of the families expected SE services to make an initial contact with the centre, but after the interview, we made it clear to the centre that it was their responsibility to refer the child. As an outcome of this research, six of the seven families with non engaged children have begun the process of engagement with SE services.

In the Central North Island context, two professionals and two families were interviewed. When we approached two families for the interviews they initially declined and said that we needed to seek the consent of the Tokelauan Council of Elders before we interviewed them. As Atkinson and Flint (2001) asserted, researchers need to have knowledge of the cultural context before approaching participants in research. It also demonstrated the importance of understanding appropriate cultural protocols in approaching families. Even though the interviewer who approached the families was from the same cultural background, she was not aware of the protocols involved. After gaining the permission of the Council we were able to re-approach and interview the families.

Engagement with SE services
There were seven families who were participating in early childhood education but who were not engaged with SE services because the centres did not have the understanding and expertise to refer them to SE services. The interviewer of one family was asked to contact the early childhood centre which the child attends and discuss or explain the referral process. In six out of the seven cases, the research process led to centre staff making contact with special education. One family with an 18 month old child is still under health services and it is likely that this child would be referred to SE services in the future. Overall, those families that had gone through health services previously in identifying and supporting their children’s special education needs, for example children with physical impairment, were more ‘visible’
for the transition to ECE centres and schools. This suggests that there should be more professional development for early childhood teachers, particularly in Pasifika centres to identify and refer children to appropriate SE services.

Two professionals suggested that school teachers also need support to identify and refer children. One said that because of the lack of referrals from teachers locally, children were missing out on support services, and that more up skilling of school teachers in this context is needed. In addition, two families felt that the ECE centres they initially enrolled their children in did not have the resources or welcoming attitudes to support their child’s needs. 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. As discussed earlier, sometimes lack of engagement with families relates to families being resistant to working with SE services, despite good intentions and persistence from professionals.

Our lalaga or ‘snow balling’ technique of following up on referrals from families and professionals usually meant that these families were either deemed not suitable to contact or difficult for us to contact them. Building relationships takes time in Pasifika context, and also our timeframe possibly limited opportunities for this to occur. Some ideas for increasing engagement overall are discussed in the priorities for improvement.

**Impact of cultural views on engagement**

It is interesting how similar cultural values and beliefs are reflected in the responses from different ethnic families and how both Island and New Zealand born view some cultural barriers that prevent participation in SE services. These cultural values include traditional perspectives held by the first generation of families in regards to the concept of special needs. This stance is a challenge for the second generation on its own, but on top of that is the burden of endeavouring to change the mindsets of their parents and family members. For example, some respondents shared that there is a lack of understanding of what the term ‘special needs’ means in relation to their parents’ views. No matter how often later generation Pacific peoples explained to their parents some general New Zealand understandings, their minds were set on the cause that leads to the special need that was a curse or act of evil. Some parents view the cause of a special need as something to be hidden and if it is shared, it will bring shame on the family. Because of these traditional views, families are reluctant to refer their children to SE services. In addition, both families (home nation and NZ born) are raised to respect elders and those in higher positions. Therefore, they tend to hold high regard for the professionals that they interact with.

It is also interesting that most families believe that working with Pasifika professionals is more effective than working with others from different cultural backgrounds. However, one of the Pasifika professionals suggested that it could be more effective to work with professionals from other cultures provided that they show cultural competence. This is confirmed by the interviewers in the focus group as they reflected that sometimes people from the same culture who may have a relationship with them creates discomfort for them and this can result in them feeling vulnerable because of perceived trust and privacy issues.

In the area of early intervention service delivery, Cullen (2002) reports that despite the inclusive socio-cultural curriculum approach to early childhood education in New Zealand, parental views from a Māori sub-sample in research to monitor the implementation of Special Education 2000 policy, provided challenges to this assumption. The diverse interpretation of cultural expectations was reflected by some parents’ beliefs “…that their child’s culture was being affirmed while others felt that not only was it not being acknowledged, but neither was its potential for assisting learning. Interestingly, not every parent believed that culture needed special consideration…referring to the supportive nature of the help these parents were receiving from their early intervention service” (p. 134).
Satisfaction with services

We had 11 families who were engaged in SE services. All were grateful for the support they received, but for various reasons there were aspects of the provision that did not meet their expectations and needs. Some of the families were satisfied with the cultural understanding of professionals that they work with. This could relate to the study described above that reported some Māori parents (in early intervention services) felt that being supported well as a family was the main criteria for satisfaction, not always just consideration of culture in their relationships with professionals.

Families valued the passion and enthusiasm that professionals showed them, as well as the good practice that staff provided. These families experienced good relationships with professionals. Others however, found lack of cultural understanding a barrier. Two participants found that labelling the child’s needs helped to access resources and support.

Families who were engaged with SE services indicated many challenges that limited their participation and satisfaction. These included personal, language, systemic, economic and cultural barriers.

Priorities to improve engagement and satisfaction with SE services

There are five main priorities identified below.

1. Improve professional cultural intelligence and sensitivity
2. Work holistically with families
3. Strengthen local support services
4. Provide professional learning and development opportunities for teachers (ECE and school)
5. Increase resources to support Pasifika families’ needs

Improve professional cultural intelligence and sensitivity

Both families and professionals felt that SE professionals needed to be more aware and more active in meeting families’ cultural needs. There were several families who reported feeling disempowered by the way they were treated by the professionals because of a lack of cultural intelligence. For example, Ofa felt that she could not ask a visiting professional to take off her shoes when she visited her home and the professional could not pick up on the non verbal cues during discussion. 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. 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, they should not be restricted to working with only Pasifika families. One Pasifika professional strongly suggested this would lead to tokenism.

Work holistically with families

Families made it very clear that they found poor relationships with professionals created a significant barrier for them to engage with SE. Frequently they 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. Families reported that they would like the same support worker to move to school with the child to preserve familiarity
and engagement. It is important to improve professional communication, collaboration and consistency across the transition to school.

Professionals need to recognize that the family has needs not just the child and proactively work with other services to meet these needs and where appropriate include the extended family in communication.

**Strengthen local community support services**
Families reported transport barriers and lack of knowledge of where to go to find out about available support. One way of addressing these challenges is by working with other services to create local family service centres or ‘one stop shops’. These need to be located in communities where parents who need this support live.

An additional way of strengthening family support is through encouraging 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.

One of the barriers Pasifika families of children with special education needs face is the stigma or shame they feel within their community. By being proactive in developing relationships and providing professional learning and development for church and other community groups, this would increase understanding and therefore engagement in the services of SE.

**Provide professional learning and development opportunities for teachers (ECE and school)**
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 six families in the study who were not engaged with SE services, the reason was that their 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. Professional learning and development is therefore suggested for early childhood and school teachers. This could enhance their ability to identify and refer cases when appropriate, and foster inclusive practices and attitudes in the day to day activities.

**Increase resources to support Pasifika families’ needs**
Families were concerned about resourcing SE needs. Providing adequate support for the transition to school was seen as a priority for some families. This includes increasing support staff time and continuity of that support. Three parents felt that lack of resourcing in regards to the funding criteria for children with high needs (ORS funding) excluded their child, for example children on the autism spectrum. Rima and Ofa discussed the need for SE information materials in a range of Pasifika languages. The materials are available from the Ministry, but services should be more proactive in distributing these resources more widely in the communities where families live. Families also discussed the need to develop and disseminate resources to support their child’s learning and development needs.
Conclusion

I am thankful for people who have taken the time to do this research. (Larry).

This project arose from the Pasifika Education Priorities: Using research to realise our vision for Pasifika learners (Ministry of Education, 2012). 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 SE from the perspectives of Pasifika families in order to increase their engagement and satisfaction with SE services provided by the Ministry. The talanoaga shared by the families in this research confirm the urgency of addressing these gaps to enhance educational opportunity.

The findings from this research substantiate the significance of underpinning Pasifika research with the three principles of Teu le va, in particular supporting collaborative relationships alongside Pasifika voices, issues and concerns. This authentic talanoaga can result in opportunities for maximizing delivery of services and policy making.
Authors

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Lin Howie, Research Associate, Manukau Institute of Technology; Head of School, School of Education

Dr Bill Hagan, Research Associate, Manukau Institute of Technology; Principal Lecturer Research, School of Education
References


Understanding special education from the perspectives of Pasifika families


Appendix A: Methodologies

Teu Le Va

*Teu Le Va – Relationships across research and policy in Pasifika education: a collective approach to knowledge generation and policy development for action towards Pasifika education success* (Airini et al., 2010), is a Ministry of Education publication which arose from a symposium held in Wellington in late 2007. The principles within *Teu Le Va* emphasise the fostering of respectful, collaborative relationships between researchers; between researchers and policy makers; and between researchers and all those involved in any given research project in the building of a sound knowledge-base for Pasifika education.

Lalaga technique for data collection

The Lalaga technique is a useful technique for accessing difficult-to-reach interconnected populations (Cohen, Mannion, & Morrison, 2011). This process progressed as we used an exponential discrimination sampling (Castillo, 2009) approach to select the participants to ensure that the sample was appropriate for the research purposes. As the links grew, further relationships were formed and more families were recruited as participants. “The task for the researcher is to establish who are the critical or Pasifika community informants/professionals with whom initial contact must be made” (2011, p.159).

Weaving the mat: A metaphor for participant recruitment

The weaving of the table mat starts from the middle with the crossing of three fine pandanus strips and then the process continues in circular motion until it grows into a big table mat. As the weaving progresses it gets complicated. Its complexity depends on how the pandanus strips are laid and ensuring that space between is strong enough to hold the mat. As the weavers engage in the process, weaving becomes a complex process as they add colourful patterns to make the outcome more aesthetic and appealing. The recruitment of suitable participants reflected the weaving process. At
first this process progressed slowly, and it gradually developed complexity with the inter connections, especially among the interviewers and families. Although the weaving of a table mat is woven in circular motion, it reflects Bishop’s (1996) spiralling effect as the chain referrals continued outwards to ensure that appropriate target participants were recruited.

**Weaving the mat: The completed mat**

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**Talanoa**

Talanoa means conversation and telling stories. Talanoa literally means “talking about nothing in particular, and interacting without a rigid framework” (Vaioleti, 2006, p. 23). Vaioleti argues that it allows more authentic information for Pasifika research than data from other research methods.
### Family Talanoa

<table>
<thead>
<tr>
<th>Name(s)</th>
<th>Ethnicity</th>
<th>Child(ren) Engaged?</th>
<th>Relationship</th>
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<td>Mother</td>
<td>South Auckland</td>
<td>30 August</td>
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<tr>
<td>Avery</td>
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</tr>
<tr>
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</tr>
<tr>
<td>Ivy</td>
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### Professionals Talanoa

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<td>Carol</td>
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### Focus group with interviewers (Talanoa, 31 August)

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<td>Charlotte</td>
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<td>Suzy</td>
<td>(Niuean radio announcer) Niuean</td>
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<td>Noama</td>
<td>(ECE supervisor) Samoan</td>
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### Focus group with families to explore suggestions for improvements to SE (Talanoa, 17 September)

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<tbody>
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<td>Ofa</td>
<td>Cook Island</td>
</tr>
<tr>
<td>Rima</td>
<td>Samoan</td>
</tr>
</tbody>
</table>
Appendix C: Glossary

Glossary of terms
Lalaga (Samoan) — the process of weaving a table or floor mat by crossing three strands of fine flax; the art of weaving.

Lea (Tongan) — words

Leo (Tongan) — spiritual essence of a person’s communication

Pasifika — a collective term that is used to refer to people of Pacific heritage or ancestry who have migrated or been born here in Aotearoa New Zealand.

Talanoa (Samoan) (n) — conversation and telling stories

Talanoaga (Samoan) (v) — having a conversation; sharing stories

Whakamā (Māori) — to feel shy, embarrassed or has a loss of mana