Parents' expectations and experiences of child-focused speech-language therapy in New Zealand

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Abstract

Background: Parental expectations for their children's speech-language therapy are similar to their expectations for any form of intervention for their children, be that medical, educational, or social. This includes an expectation and need for effective communication between parents and professionals. As well as exploring parental expectations and experiences of speech-language therapy, this study also aimed to discover factors that may help or hinder the meeting of parents' expectations. This study also aimed to better understand parents' experiences in the light of family centred care.

Method: Seventeen parents completed a survey regarding parental expectations and experiences of their child's speech-language therapy. Four of these parents also participated in in-depth interviews. Results from the survey were analysed using descriptive statistics and the interview data along with three survey questions were transcribed and analysed thematically.

Results: Five overarching themes emerged from the data, namely expectations, working as a team, funding, important aspects of therapy, and considerations. Key findings from the survey included parents' expectations of being involved in the planning and therapy process of their child's speech-language therapy and parents' expectations of progress.

Discussion: Communication between parents and speech-language therapists is important to allow not only for articulation of parental expectations but also to ensure that the therapy is tailored appropriately to allow for the most effective use of the service. Encouraging parents and highlighting progress are important aspects of speech-language therapists' role, in addition to providing therapy in a manner that benefits both the child and the family.

Conclusion: The small sample size involved in this study limits generalisation of results. However, consideration of these findings in speech-language therapy practices, may enhance therapy for children who experience difficulty developing communication.

1. Introduction

Expectations are part of the human experience. These arise from and impact on our interactions across our social environments (Russell, 2003). Expectations are ideas for what the future will hopefully hold and may relate to an individual's life or to others. It is possible for expectations to be either positive or negative, for example expecting a poor performance on a test, or expecting you're your meal will be delicious. Often when an expectation is unmet, or reality turns out to be something different than what was expected, the experience can have the opposite emotion attached to it. For example, if someone was expecting to have a boring day, but they happened to meet an old friend, the experience of the day will likely have more positive emotions attached to it than expected. Expectations can be based on life goals or conditioned by experiences. For example, expectations of a career achievement or a cup of coffee from a café. Family members and close friends can shape our expectations through the relationships we have with them and each other (Diamond, Russon, & Levy, 2016). These expectations may relate to interactions with others, goals and achievements, and our children.

When people become parents, their expectations begin to relate to their child/ren. These include developmental expectations related to different aspects of development such as physical, social, and communication. Many of these expectations relate to observed differences between children of a similar age. For example, if a parent attends a parent-child social group and children are walking – a parent of a child not yet walking may develop an expectation that their child will begin walking soon.

Related to developmental expectations are parents' expectations for their children's health and education. This is particularly relevant when a parent has a child that may require treatment for health conditions or any extra services to support developmental delays or differences (Russell, 2003). These expectations may be unconscious and can come to light when they are not met, or there is a need to fight for them to be met. When expectations are thought through and voiced to each other, parents and professionals can begin to work together in a trusting relationship (Russell, 2003). When it comes to seeking help for their children's needs, parents will bring their own ideas as to what their perceptions of support are, often based on knowledge of what has worked or not in the past (Baxendale, Frankham, & Hesketh, 2001; Klatte & Roulstone, 2016).

Parents have a great deal of knowledge about their children and how any difficulties they experience affect their daily lives (Lindsay & Dockrell, 2004; McCormack, McLeod, Harrison, & McAllister, 2010). Parents also view their children differently from professionals. This likely stems from the significant time and variety of contexts that parents spend with their children as they grow up. Therefore, parents have the potential to offer insights and perspectives to complement the experience and skills of professionals (Cress, 2004; Glogowska, 1998; Lindsay & Dockrell, 2004; Paradice & Adewusi, 2002). From an educational perspective, parents expect that their child will learn, will succeed, and that their child will be supported in their learning (Yamamoto & Holloway, 2010). When support services are needed for their child, be they medical, social or educational, parents have expectations. These may include that their child will show progress, that they as parents will be involved in some way, and that the service provided will be designed to meet both their child's needs as well as their own needs (Lyons, O'Malley, O'Connor, & Monaghan, 2010; Russell, 2003).

Parents have been involved in their child's learning since they have been born, and their involvement with their child's learning can help encourage their child to be more engaged with their own learning (Goodall & Montgomery, 2014; Goodall & Vorhaus, 2011). Parental involvement in their child's learning has shown to be important in educational settings as well as in speech-language therapy (Goodall & Vorhaus, 2011; Watts Pappas & McLeod, 2008b). Parents are likely to arrive at therapy appointments with their own ideas as to what the therapy will look like, how it will be conducted, as well as knowledge of what has been successful in the past (Baxendale et al., 2001; Klatte & Roulstone, 2016). When looking at parental involvement in the wider allied health setting, parents may want the clinician or professional to take the lead during intervention sessions (Watts Pappas & McLeod, 2008a).

There is limited international, and no New Zealand-based research that describes parental expectations of their child's speech-language therapy. The majority of the international research on parental expectations of speech-language therapy focus on parents with children with a particular diagnosis, such as speech sound disorders. This study set out to determine what the expectations and experiences parents of children who receive speech-language therapy (for any diagnosis) in the New Zealand context are. The pilot study involved a survey of 17 parents of children receiving speech-language therapy

support. As well as this, 4 of the parents also participated in follow-up interviews to further explore their expectations and experiences.

1.1 The speech-language therapy context

Speech-language therapists assess and treat people of all ages who have difficulty with any area of communication and/or swallowing (Royal College of Speech and Language Therapists, 2015). Some of the areas of communication that speech-language therapists work with include delays or disorders related to speech sound development, language, social communication, and cognitive aspects of communication (American Speech-Language-Hearing Association, 2017). Speech-language therapists work in a variety of health, education, and rehabilitation settings. These include hospitals, schools, rest homes, rehabilitation and care facilities, private practice, and University-based clinics (Royal College of Speech and Language Therapists, 2015). Referrals to speech-language therapists are typically made by health, education and rehabilitation professionals such as medical specialists, general practitioners, and teachers. In many cases parents also approach speech-language therapists with concerns or questions about their child's development.

During initial consultations, speech-language therapists typically conduct case history and rapport-building interviews followed by specific assessment of the client's skills. This could include a client's ability to say speech sounds, recognise and use different aspects of language, or the client's ability to swallow safely. The purposes of assessment include identification of clients' strengths and challenges, establishing a baseline of functioning to enable measurement of change, establishing goals for therapy, and looking at what methods of intervention will be most appropriate (MacRoy-Higgins & Galletta, 2014; Paul & Norbury, 2012). Assessments involve gathering and interpreting information, then communicating with the client, their family, and any other members of the support team (MacRoy-Higgins & Galletta, 2014). Assessments are often a mixture of formal and informal assessments depending on the needs of the client and consist of four main methods. These are: case history questionnaires and interviews to gather information about the client to help focus the assessment; norm-referenced tests which allow the client's performance to be measured against a sample of similar individuals; criterion-referenced procedures which compare the client's abilities to predetermined

expectations such as what communication skills are commonly displayed by a 12-18 month old child; and observational tools which may occur in a more informal environment (MacRoy-Higgins & Galletta, 2014). Assessments are best carried out as part of a team, in which parents are a vital members, so as to allow for a holistic view of the client (Paul & Norbury, 2012). It is also important to have good communication between the members of the team, including the parents, or parents can see this process as very isolating (Band et al., 2002). Once the initial assessment has been completed, goals can be set, and intervention can begin.

The purpose of intervention is to support changes in behaviour. In this context, the term behaviour refers to speech sounds, ability to comprehend or use language, social communication, swallowing, etc. For example, the increased of speech sound production or learning strategies to help manage a stutter (Roth & Paul, 2014). In the speech-language therapy context, these changes typically relate in some way to maximise the client's ability or potential to communicate or swallow more effectively (Roth & Paul, 2014).

There are many different interventions which fall along a continuum of naturalness which helps illustrate how much a certain intervention corresponds to everyday situations (Fey, 1986; Roth & Paul, 2014). The factors that affect the level of naturalness are the activity, the physical context of the intervention, and the social context or who conducts the therapy. Interventions then range from clinician directed approaches to client centred approaches with some hybrid approaches in the middle of the continuum. The approach used for a particular client may change as their therapy progresses to best fit the needs of the client and different approaches may be used to target different goals (Paul & Norbury, 2012; Roth & Paul, 2014). Parental involvement levels in both assessment and intervention can vary; however, it is very important especially when working with families from different cultural backgrounds (Paul & Norbury, 2012).

Communication within the therapy context is an important aspect for ensuring that professionals are aware of family preferences and concerns. Effective communication also helps professionals learn about children's and parental needs as well as the influence of home, preschool, and other environments (Marshall, Goldbart, & Phillips, 2007; Rice & Lenihan, 2005). Clear and appropriate communication

can also help increase parental engagement and participation which in turn can help increase a child's engagement (Glogowska & Campbell, 2000; Goodall & Montgomery, 2014; Goodall & Vorhaus, 2011). Because the relationship and partnership between parents and speech-language therapists, or any professional, has the potential to influence therapy outcomes and parental satisfaction, it is important for speech-language therapists to have an awareness of parental needs and perspectives so that their practices can enhance the lives of parents and their children (Edwards, Brebner, McCormack, & MacDougall, 2016). Therefore, it makes sense to have a service delivery model that is focused on communicating with families and involving them in their child's treatment programme. Family centred care is a service delivery model that endeavours to achieve this.

Family centred care is a service delivery model which is used in a variety of contexts by many different professions concerned with helping children. It is a model that is regularly noted as best practice for early intervention in child development fields (Dunn, 2000; Fordham, Gibson, & Bowes, 2012). A review of family centred approaches across a range of field is detailed below in order to provide a comprehensive understanding of parents' wants and expectations related to interventions for their children.

1.2 Family centred care – a background

Family centred care is a model of practice that places parents, their children, and wider family at the centre of intervention processes (Shields, Pratt, & Hunter, 2006). The following section looks at the development of family centred care over the last few decades over a range of health and medical professions and settings.

Family centred care developed out of post-World War 2 research by Bowlby (1953) and Robertson (1958). Experiences from the war and afterwards highlighted the detrimental effects of separating children from their parents, especially in traumatic situations. Children who were separated from their families experienced high levels of mental health issues and negative effects to the wellbeing of the child and their family were also noted (Jolley & Shields, 2009). During this time, health care for children was based on the medical model of health. This model was child and treatment focused with

the professionals making the decisions for treatment goals and objectives that they felt were most appropriate without family input (L. Rouse, 2012). Change was slow, but eventually hospitals changed from being somewhere your child was handed over to the medical staff to care for, to somewhere parents are often expected and encouraged to stay with their child. These changes were often supported by the perseverance of parent advocacy groups (Jolley & Shields, 2009; Rosenbaum, King, Law, King, & Evans, 1998). The Platt report (1959), which helped provide a scientific basis to the argument of family centred care, gave recommendations relating to provisions for mothers to stay with their children, as well as others focused on making hospitals a more welcoming place for children. These recommendations helped to bring about change in the provision of medical care to children (Chenery, 2001; Foster, Whitehead, & Maybee, 2010; Platt, 1959). The advent of family centred care has seen health care services begin to follow a more social model with partnerships between parents, families, and professionals at its core (L. Rouse, 2012).

Family centred care is a social model of service provision based on working in partnership with families (Arango, 2011; Blocher-Rubin & Krabill, 2017; Franck & Callery, 2004; Hodgetts, Nicholas, Zwaigenbaum, & McConnell, 2013; Law et al., 2003; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007; Rosenbaum et al., 1998; E. Rouse, 2012; L. Rouse, 2012; Ryan & Quinlan, 2018). It is based on family systems theory and ecological systems theory in realising that families are interconnected, each member of the family has an impact on other members of the family, and the importance of all members' needs (Jung, 2010; Mandak & Light, 2018a, 2018b; Rosenbaum et al., 1998; L. Rouse, 2012). With family centred care, it is important to see the child in the context of their family, not solely in the context of their diagnosed condition (Ziviani, 2011). The core elements of family centred care are respect, trust, open communication, collaborative decision making and the willingness to negotiate; empathy, active listening, and relationship building are also important components (Arango, 2011; L. Rouse, 2012).

Family centred care is a strengths-based approach, as it advocates working with family and client strengths to help support areas of difficulty (Arango, 2011; Braun, Dunn, & Tomchek, 2017; Cress, 2004; Dunst, Trivette, & Hamby, 2007; Fordham et al., 2012; Russell, 2003). A strengths based focus

is important because, focusing solely on the difficulties can run the risk of implying parental incompetence and that the child is also deficient (McWilliam, 2010). As such, recognising and acknowledging child, parent and family strengths are important. Empowering parents to be decision makers that work in partnership with professionals, is something that family centred care helps facilitate; it also realises that the people who spend the most time with a child have the greatest impact on them and this tends to be the child's family, especially in the case of younger children (Dunst & Trivette, 1996; Jung, 2010; Raghavendra et al., 2007; E. Rouse, 2012).

Family centred care must be tailored specifically for each family. Families as well as their strengths, capabilities, available resources, and situations are unique (Hanna & Rodger, 2002). Each family will also have different expectations and wishes regarding their involvement in their child's therapy, and this can change over the course of the therapy (Franck & Callery, 2004; Marshall & Goldbart, 2008). In order to adapt therapy to suit family needs, abilities and requests, be that speech-language therapy, physiotherapy, or some other medical intervention, there are some elements and concepts that are important to consider. The following section looks at some of these.

1.2.1   *Fundamental aspects and components of family centred care*

Dunst and Trivette (1996) conducted a literature review focusing on empowerment, effective help-giving practices, and family centred care practices. Their findings suggested that all three ideas and practices are linked together as each is a more specialised case of the previous practice. First of all, empowerment was seen to be as a way of enhancing competency by understanding that people have existing strengths and the ability to increase their competency. Positive relational practices combined with the control in the relationship lying with the parent or person seeking help were seen to be important elements of effective help-giving. Dunst and Trivette (1996) tied help-giving practices and empowerment to family centred care by suggesting that family centred help-giving or care will have empowering consequences, beyond high quality care that is just focused on fixing a particular problem. This involves professionals utilising positive relational practices, believing that their clients (and their parents) have existing skills and abilities as well as the potential to become more competent, and actively and meaningfully involving clients and their parents in the therapy or intervention process.

Rosenbaum et al. (1998) suggested that family centred care was based on 3 different premises. The first premise is that parents have specialist knowledge of their children and want the best for them. This means that family centred care needs to be a collaborative partnership and that services are offered in an accessible manner both location wise but also in a way that parents understand. The second premise focuses on the uniqueness of families. Because of this, professionals need to endeavour to understand and interact with parents on the parents' terms not theirs. The third premise expands on the idea of how children develop best in a supportive family environment and can be affected by the stress of others. Recognising that families have needs other than the child's needs and supporting them is an important part of this premise (Rosenbaum et al., 1998).

Trivette and Dunst (2000) identified 17 evidenced based practices that are family centred and grouped them into four categories as seen below.

- Collaboration and sharing responsibilities
- Strengthening family functioning
- Tailoring therapy to families
- Utilising families' strengths   (Espe-Sherwindt, 2008; Trivette & Dunst, 2000)

The first category focuses on the development of relationships to allow for collaborative family identified outcomes, the sharing of complete information in a manner that the family understands, as well as being culturally sensitive so that families can make informed decisions and families and professionals can work together collaboratively. The second category is focused on supporting families in ways to allow them to be able to have a life separate from doing therapy for their child, as well as building parental confidence. This includes using resources to build on parents' sense of confidence and competence. Understanding that families are unique and have different beliefs and values and then providing services and resources that incorporate this as well as attempting to minimise extra stress by being sensitive to the unique makeup of each family is the essence of the third category (Espe-Sherwindt, 2008; Trivette & Dunst, 2000). The final category is about utilising families' strengths and assets in interventions to help strengthen family competency and confidence

A key feature that differentiates family centred practices from other approaches is the relational and participatory components (Dunst, 2002; Dunst, Boyd, Trivette, & Hamby, 2002; Dunst & Trivette, 1996; Mandak & Light, 2018b). Relational skills are not only those typically associated with being a good clinician, for example active listening and empathy, but they are also tied into professional beliefs and attitudes regarding the positive abilities and competencies of families. Participatory practices include those such as providing families with opportunities to be involved, to make choices and actions towards goals that they chose, as well as those that are focused on providing individualised and flexible services that are responsive to family concerns and needs (Dunst, 2002; Dunst et al., 2002). Family centred care, is suggested to be a way of engaging families, as it is an approach that helps to match practices to families' concerns, priorities, and desires. There is however a tendency by professionals across many different fields to claim that their services are family centred when the evidence is to the contrary (Dempsey & Keen, 2008; Dunst, 2002; Edwards et al., 2016; Harrison, 2010; Mandak & Light, 2018b; Ryan & Quinlan, 2018).

Following a review of the literature on family centred care and practices, Franck and Callery (2004) found that the various models of family centred care "share a common belief that, over time, the family has the greatest influence over a child's health and wellbeing" (p. 260). Elements that the different models of family centred care all include are respect for the child and their family, recognition of the importance of the family to the child's wellbeing, and partnership – professionals working collaboratively with families (Franck & Callery, 2004).

1.3 Parental context

The main premise of family centred care is to enhance services for families (Foster et al., 2010). While different cultures and funding practices shape the way family centred care is implemented, it is practiced globally in both developed and developing countries. A number of questions arise regarding family centred care. Specifically, what do parents want and need, are these needs being met in parental interactions with professionals, what is missing from existing services, and what do professionals perceive as parents' needs and wants? The following section summarises research examining parental expectations, parental needs, as well as barriers and areas for improvement.

1.3.1   Expectations

Edwards et al. (2016) examined the expectations of parents of children with autism spectrum disorder (ASD) regarding speech-language therapists. The study involved semi-structured interviews with 14 parents, whose responses related to the qualities that parents were seeking in speech-language therapists were analysed using thematic analysis. Participants were also asked to complete a short questionnaire to collect demographic data and information relating to the interventions that had been implemented. One of the limitations of this study was that the participants' experiences were based in one region and due to service delivery varying across not only the same country but internationally this may limit the degree to which these findings can be applied to other parents. Two main themes emerged from the analysed data, being partnership and effective therapy. Working in partnership with speech-language therapists was valued as well as the speech-language therapists delivering effective therapy. For this study, the most important aspect for parents was achieving positive outcomes, and these parents were willing to sacrifice relationships with the therapist in order to achieve this. There were also other qualities and aspects that were important to the parents. These included; collaboration in therapy, therapist honesty when they were unsure or when the therapy was not working, parents both receiving and providing information, shared values around child development and behaviour management, emotional support, having a holistic approach to therapy, tailoring the therapy to fit the child, and having a good relationship with the child (Edwards et al., 2016).

The foci of an Australian study were the parental beliefs and experiences of their involvement in speech-language therapy for their children with speech sound disorders (Watts Pappas, McAllister, & McLeod, 2016). This study involved several interviews with seven parents of six children with speech sound disorders. The parent(s) of each child (for one of the children both parents were interviewed together) were interviewed three times over the course of a block of intervention. The data collected from the interviews was analysed using thematic analysis and three main themes became apparent. These themes were; doing the right thing by my child, factors impacting on the intervention, and reflecting on the experience of speech intervention. All the parents in this study were from one city in Australia, who were receiving public speech-language therapy services which may limit the extent that these results

would apply to more rural parents whose children were receiving services from a different service provider. Many different factors were important to parents. Establishing a shared frame of reference and having speech-language therapists know what motivated them to be involved was important for facilitating parental involvement. Early intervention was important for parents, as they wanted therapy to begin as soon as a problem was realised, especially before their children started school. Parents saw their roles and responsibilities to be actively present during intervention sessions and to work with their child at home. Working at home with their child was seen as vital, but it was easier when the therapist provided material to facilitate this. Parents can feel overwhelmed with home practice, but Watts Pappas et al. (2016) suggested that this may happen more with more complex or pervasive disabilities. Negative experiences often related to the child having a negative experience and/or the therapist not respecting parents'. Parents appreciated effective communication – knowing what was happening and being informed in a manner that they understood. Parents were happy with their level of involvement, as they saw it as the most effective use of the service, however therapists needed to be aware that parents may at times wish to be more or less involved and need to follow parents' lead regarding this.

1.3.2   Parental needs

Parental expectations are important, but are there other aspects that they may not have expectations around, or that can help their expectations being articulated and met? What are the needs that parents are not aware of when they begin therapy interactions, that become apparent during therapy? This section explores some of these needs.

1.3.2.1 Communication

The influence of three aspects of communication, being caring, interest, and collaboration on parent/therapist communication and satisfaction with a child development centre were examined in a study by Bachner, Carmel, Lubetzky, Heiman, and Galil (2006). The most important aspects reported were caring and collaboration. Caring, and the expression of this, by professionals helped to develop relationships and may have helped increase parental engagement. Collaboration helps build parental confidence in the therapists, in the therapy process, and in their own abilities. It also helps increase

involvement as collaboration fosters mutual decision making and sharing of responsibilities. Bachner et al. (2006) also found that parental education levels may affect collaboration as more educated parents may feel more comfortable asking questions and it may be easier to share information with them. Therefore, care needs to be taken to ensure that for parents who are less confident in asking questions and are not as easy to share information with, are not disadvantaged in the collaboration process.

Negotiation around roles and parental participation is an important aspect of family centred care. Corlett and Twycross (2006) reviewed the literature surrounding nursing staff's negotiations with parents. Clear, effective communication was important to allow role negotiation to take place and for both nursing staff and parents to articulate their expectations relating to participation. Parents found that lack of communication and information sharing was a major issue as they felt it limited their ability to negotiate with the medical staff. Corlett and Twycross (2006) found that nurses need to take the responsibility of establishing relationships and communication with parents at the beginning, rather than waiting for parents' confidence to increase over time. This finding of the professional needing to take the responsibility in taking the lead in relationship building is carried over into other fields such as speech-language therapy (Mandak & Light, 2018b).

Collaboration with parents is encouraged by national professional speech-language therapy associations (e.g. American Speech-Language-Hearing Association, 2010, 2016; New Zealand Speech-language Therapists' Association, 2012; Speech-Language & Audiology Canada, 2015; Speech Pathology Australia, 2015). Creating a collaborative space that allows parental views and opinions to be of equal value to speech-language therapists that can help build effective working relationships is important, and effective communication is a large part of this (Auert, Trembath, Arciuli, & Thomas, 2012). Shared frames of references can help parents and professionals approach situations in a similar manner, or help them understand and be sensitive to each other's views, concerns, and expertise (Blocher-Rubin & Krabill, 2017; Cress, 2004; Lyons et al., 2010).

The way parents see their roles in supporting their child during speech-language therapy, can change over time as Davies, Marshall, Brown, and Goldbart (2017) found in their study exploring this. Parents often have a firm idea of their role as advocate for their child, although parents may need some support

in this area as well (Bruns & LaRocco, 2017; Davies et al., 2017). When being involved with their child's speech and language therapy, parents often have a less defined idea of what their role is, although they expected to learn how to support their child. As parents began to feel more confident and knowledgeable, many parents found their roles changing. Davies et al. (2017) suggest that parents are often expecting to be learners in how to support their child and so speech-language therapists may need to support them in this in order to help facilitate parental involvement.

Communication between school-based speech-language therapists in America and parents of children with language impairments was examined by Tambyraja, Schmitt, and Justice (2017). In this study, communication was defined as any form of contact with parents, including home practice which was the majority of the communication. It was found that while the evidence suggests that speech-language therapists try to communicate with parents regarding assessment and planning of service and parental involvement is valued, communication with parents in school-based settings is difficult. In this study, communication was extremely varied possibly because the speech-language therapists were more likely to have consistent communication with parents who were responsive to it (Tambyraja et al., 2017).

Communication is an important prerequisite for a healthy functional relationship and the value of having relationships with parents has not changed over time (Dalziell, 2011). So, in order for speech-language therapists to build relationships with parents and their children clear, consistent communication is needed. What else are parents needing in order for their relationships with their speech-language therapists to thrive?

The relationship between the nursing staff and the family is central to family centred care as Hutchfield (1999) found in her analysis of family centred care from a nursing perspective. This relationship however needed to be based on respect for the family and their views and opinions and on open and honest communication. Other aspects that were important to family centred care were also found. Some of these aspects included parents wanting to be involved, nurses being willing to allow families to be involved, nurses being prepared to build a relationship and collaborate with the families, and sufficient time being available to explore and discover families' concerns. The time needed to build relationships

with parents and to support them were issues that Hutchfield (1999) found that could hinder the provision of family centred care.

A literature review was conducted by Hanna and Rodger (2002) who concluded that professionals needed to realise that parents bring a great deal to the collaborative process and to actually learn from parents' perspectives. Parents are not a homogenous group and as such they have individual needs and preferences. Because of this, professionals need to try and understand parents' perspectives as they may need to balance provision of therapy with other competing demands. Involvement of families in the planning of intervention and in the intervention itself are key to family centred care (Hanna & Rodger, 2002).

Parents know their children, especially when their behaviour is not normal and as such have great amounts of information to share (Franck & Callery, 2004). Therefore, parents should be enabled to choose the roles that they want to adopt for the provision of therapy, whether these roles be more active or more passive roles, it is their choice. Choosing the roles that they want is important because different families will want and need different things from professionals (Iacono & Cameron, 2009).

Boshoff, Gibbs, Phillips, Wiles, and Porter (2018) found that for parents of children with ASD, the initial relationship with professionals is very important. These initial relationships often occur when a diagnosis is being sought and establishes how parents will view any other professionals. In order for good relationships to be built, professionals need to acknowledge parents' concerns and observations as well as communicating with them openly, honestly and frequently (Boshoff et al., 2018). Relationships are the core on which family centred care is built and families both value and can expect partnership based relationships with health professionals (Harrison, 2010).

Another aspect to communicating successfully with parents is understanding what resources they have available for their child's therapy. Some parents may only have a limited amount of time, whereas others may have plenty of time, but be unable to travel to therapy sessions and there can be a financial and emotional cost to both families and professionals (Marshall & Goldbart, 2008; Shields et al., 2006). Understanding this, is important in order to fit therapy to parents rather than parents having to fit the

therapy. As such, negotiation around goals is important to allow for parent's priorities to be heard and implemented into therapy (Carroll, 2010). Communication is needed in order to fit therapy to families and their situations and to make the therapy meaningful (Jasmin, Tétreault, Larivière, & Joly, 2018; Jung, 2010).

Parents' views of their relationships with allied health professionals and allied health professionals' views of the role of parents were examined by Dodd, Saggers, and Wildy (2009). Successful implementation of family centred care was seen to be more than focusing on the individual characteristics of each family and it is also more than just shifting the responsibilities to the family. Professionals can see family centred care as something that all families will be proactive in seeking care for their child and this is not necessarily what every family wants or has the necessary resources to achieve (Dodd et al., 2009; Franck & Callery, 2004; Hanna & Rodger, 2002). A lack of shared understanding, such as how much time a particular family has to devote to the child's therapy, can limit partnerships between families and allied health professionals. The level and type of involvement families have with their child's treatment can change over time and professionals need to be able to acknowledge this and respond accordingly. In order to prevent the responsibility for the therapy, just being shifted to families, professionals need to ensure that families have the information, skills and resources to adequately negotiate roles.

1.3.2.2 Involvement

Parental involvement can have positive effects on their children's learning and development (Goodall & Montgomery, 2014; Goodall & Vorhaus, 2011). Considering that speech-language therapy involves supporting children to learn new skills, parent engagement in their child's therapy can be very influential. It is therefore important to understand parents' perspectives on their involvement in their children's therapy. Similarly, increasing our understanding of how professionals involve parents will likely support further collaboration, as it will become easier to see what practices are helpful to foster this. Parents have varying amounts of participation in therapy, which can change over time, as parents and their individual situations are unique (James & Chard, 2010; Mandak & Light, 2018b). The therapy approach and strategies used need to suit each family and their situation. Involving parents in decision

making is one way of ensuring that suggested management strategies are not asking more of families than they are able to give (Chauhan, Prasad, Rai, & Khurana, 2017; McCormack et al., 2010). It is also important to focus on parents' goals not professionals' goals for the child in order to facilitate parental involvement in therapy; this is a process that requires collaboration between parents and professionals (Cress, 2004; Thomas-Stonell, Oddson, Robertson, & Rosenbaum, 2009). Parental involvement in their child's therapy is one way of empowering them in situations that can potentially be disempowering for parents, as they may feel that the situation is beyond them and they do not have the right skills to help their child (Auert et al., 2012; L. Rouse, 2012).

In their survey of Australian speech-language therapists, Watts Pappas, McLeod, McAllister, and McKinnon (2008) considered how parents were involved into the therapy process. 277 speech-language therapists completed a questionnaire focused on the speech-language therapists' involvement of parents in interventions aimed at speech sounds and their beliefs around working with parents. There was only a limited number of speech-language therapists who completed the questionnaire (277 out of 2200 contacted) and this was a self-report measure that was not independently verified so the results may not show the complete picture of Australian speech-language therapists working with children with speech sound disorders. While the speech-language therapists believed that family involvement was important, the majority of speech-language therapists had stronger beliefs about and involved parents more in the provision of service, rather than service planning. The majority of parental involvement in therapy was through home practice (Watts Pappas et al., 2008).

Nursing staff and families felt that family centred care was important in a study conducted by Coyne (2015) examining nursing staff's and families' perspectives of family centred care. Family centred care that occurs by necessity, rather than by choice, is in conflict with the overarching philosophy of family centred care. Nurses felt that it was important that families had a choice regarding their level of involvement, however nursing staff did rely heavily on families to undertake basic cares, such as dressing and feeding, which could lead to families feeling like they always had to be there to ensure that their child had no unmet needs. There appeared to be no real negotiation around roles and families were unsure of where they fitted in and lacked information about what their role was (Coyne, 2015).

There can be inequalities in the roles of families and nurses and Butler, Copnell, and Willetts (2014) found that often either the families wish to be more involved or that nursing staff were wanting families to be more involved.

Sugden, Baker, Munro, Williams, and Trivette (2017) examined how speech-language therapists in Australia who work with children with speech sound disorders are involving parents into their therapy. The most common way of involving parents was through the use of home practice' however, home practice tasks were often not completed due to them not fitting into family life or lack of parental understanding about the tasks or the importance of them. The main reason to involve parents in their child's therapy was to increase the amount of therapy provided and to increase therapy outcomes. The majority of the speech-language therapists who participated in the study believed that family involvement was essential to the effectiveness of therapy and that families should be involved, as well as being able to choose their level of involvement. However, there was a disparity in the number of speech-language therapists who reported involving parents and the number of speech-language therapists who believed that families were happy to be involved in therapy. Speech-language therapists were aware that parents may not be able to or feel able to participate in parent training but saw involving parents in speech-language therapy as another way of managing service delivery barriers, such as limited amounts of therapy time. It was suggested that speech-language therapists need to partner with parents in order to determine the level of involvement that each parent wants and to tailor home practice tasks and practice schedules in order to suit parents (Sugden et al., 2017).

1.3.2.3 Information

Care needs to be taken when providing information to families that it is done in a sensitive, timely manner and in a way that they are able to understand, as too much information can be overwhelming (Shields et al., 2012). Families' need for information can change over time and as such professionals need to be more intuitive about this (Rice & Lenihan, 2005). Information is the foundation of family centred care and is needed for informed decision making and therefore forming an equal partnership with professionals (Butler et al., 2014). The availability of information for parents can vary and is often seen as something that is missing from services (Fordham et al., 2012; Paradice & Adewusi, 2002;

Raghavendra et al., 2007; Ryan & Quinlan, 2018). Clear accessible information that is unbiased and available over time is important for parents (Goodall & Vorhaus, 2011; Ziviani, 2011).

What do speech-language therapists think that parents of children with ASD expect of them? Trembath, Hawtree, Arciuli, and Caithness (2016) researched this in their survey of Australian speech-language therapists. Each parent is different and as such they approach therapy and their relationship with the therapist differently. Prior experiences can have a large impact on what parents are expecting. The speech-language therapists involved in the study, agreed that parents have the right to know about the research evidence for the treatment that was being provided, however they differed in how they perceived parents' eagerness to find out about this. Trembath et al. (2016) then suggested that it is the speech-language therapist's responsibility to communicate with the parents regarding the possible benefits and disadvantages of different interventions. Speech-language therapists felt that it was important that parents became informed consumers of the interventions that their children were receiving and spoke of the different ways they attempted to structure parents' journey to prevent them either becoming overwhelmed with information or on the other hand having too little information.

Auert et al. (2012) found that parents felt that it was part of the speech-language therapist's role to involve parents in decision making and in order for this to happen, parents needed information. There seemed to be a direct relationship between the amount of information that a parent was provided and their ability to make informed decisions, as well as a mismatch between what parents wanted to know about the therapy and what information was provided (Auert et al., 2012). Similar findings were reported by McNeilly, Macdonald, and Kelly (2017) as they explored parental experiences of participating in decision making for their children. Information was an important component of the article with parents identifying provision of information about their child's conditions as one of their core needs (McNeilly et al., 2017). Access to information could affect parents' participation and before diagnosis parents tended to be proactive in searching for information.

Professionals can be reluctant to appear uncertain when sharing information, but parents value when professionals share their uncertainty as this can help build trust between the parent and the professionals (Butler et al., 2014; Caronna, Augustyn, & Zuckerman, 2007). Parents want to know what is happening

with their child, even if it is not good news, as it can help them have a sense of control over the situation (Bachner et al., 2006).

1.3.2.4 Other parental needs

Parental experiences of their children's hospitalisation following an acute injury or illness were examined by Gasquoine (2005). It was found that parents valued the little things that the nursing staff did for them that were not necessarily directly related to their child's treatment. These included remembering their child's name, supporting parents while their child was in surgery, and the general caring attitude that the nursing staff had towards their children. These experiences were contrasted with others when this did not happen and left parents feeling unsupported (Gasquoine, 2005).

Looking at how to best support families through family centred care, Dempsey and Keen (2008) found that there was a strong relationship throughout the literature between help giving practices and parent reported empowerment. Empowerment for parents is important as it helps them to have a sense of control over a situation that potentially could be very isolating and stressful (Dempsey & Dunst, 2004; Glogowska & Campbell, 2004). Effective communication can help to empower parents (Auert et al., 2012). Help giving practices need to be more than just relationship building, they also need to have a participatory component, such as helping parents to be involved with decision making and planning, in order to allow them to have the most benefit to families (Dempsey & Keen, 2008; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Dunst, 2002; Dunst et al., 2002).

Parental views of speech-language therapists and speech-language therapy services for their children, who use augmentative and alternate communication (AAC) devices, were researched by Marshall and Goldbart (2008). These results included aspects such as parents having specialised knowledge of their children and needing this knowledge to be taken into consideration, information being available at all stages as different families will need more or less information at different times, and the fact that parents differ in the amount they are able to or want to be involved. Parents found that it was important for professionals to be aware of things that may hinder parents' involvement, such as lack of time or resources, and to express this, as well as acknowledging the fact that having a child who uses AAC to

communicate is not easy and as such parents' ability to engage with therapy may vary over time (Marshall & Goldbart, 2008).

Fereday, Oster, and Darbyshire (2010) looked at what parents were wanting from generic health professionals in Australia. A generic health professional or GHP was defined as someone "who does not work specifically with children with disability or their families or carers, but who provides an element of 'general' health service provision that children with a disability and their families may be likely to access" (Fereday et al., 2010, p. 624). Families wanted family centred care, as they found that GHPs were likely to ignore the wider implications of the disability and could overload families with interventions. The relationship between the family and the GHP was important with open communication, trust, and respect being important elements. Families also were wanting information to be provided by the GHPs, especially in relation to funding and extra services for their children.

Continuity of care is something that is valued by parents as they are able to talk to the same person consistently and build a relationship with them (Butler et al., 2014; Carroll, 2010; Robert, Leblanc, & Boyer, 2015; Ryan & Quinlan, 2018). Continuity of care can also have positive impact on the child's care as relationship building with professionals can result in the professionals being able to provide more individualised services (Fereday et al., 2010). This is something that can be better developed in some services (James & Chard, 2010).

Acknowledging the validity of parents' concerns and addressing them promptly is crucial, as Ryan and Salisbury (2012) found that failure to engage with parents' concerns led to parents feeling isolated, frustrated and even humiliated. It also affected their relationship with that professional. Parents' emotions regarding their child and the situation also need to be addressed and professionals can view parents' needs differently from parents so communication is needed to ensure that needs are met (Butler et al., 2014).

In order to make family participation in therapy feasible, the service should to be able to change to reflect the family's needs throughout the therapy process. Hodgetts et al. (2013) found that sharing information was the biggest need, but that rapport building was also important. When it comes to

rapport building, parents value professionals taking the time to get to know their child and acknowledging that the parents are experts on their child (McNeilly et al., 2017). In order to have good relationships with professionals, parents needed to feel like they are listened to and understood.

Parental experiences of support services for their children who have developmental disabilities were studied by Robert et al. (2015). There was an interesting finding in that parents that were more satisfied with the services they received tended to have goals focused on the here and now, whereas parents that were less satisfied tended to be more concerned with looking to the future and maximising their child's learning and potential. Also, parents with more positive experiences tended to see the professionals as the experts and felt that they themselves did not have enough skills contrasting to parents with more negative experiences who saw themselves as the experts on their child and wanted to be more involved with their child's therapy. This suggested that the services needed to fit families' needs and abilities better. Families found information was very helpful, when it was available, as it could have a positive effect on their environment. Parents wanted to be involved with decision making and for professionals to recognise and value the time and effort that parents were putting into their children (Robert et al., 2015).

An important skill for parents to have is the ability to advocate for their child and for themselves. Bruns and LaRocco (2017) researched how to support and build parents' abilities to advocate. Building relationships with parents is important as well as supporting them and working towards their goals, not professionals' goals. Asking the right questions is another skill that professionals can help develop and support (Bruns & LaRocco, 2017).

Communication and collaboration between parents and professionals were the main themes of parent focus in a study conducted by Ryan and Quinlan (2018) examining parental perspectives of various health and education services for their children with disabilities in Ireland. Parents wanted a collaborative relationship with professionals, sharing information, decision making and expertise. When it came to whether there were unmet needs or not, it tended to depend on the relationship with professionals in question, as when the family was in a relationship with professionals where they were respected and supported, professionals seemed to be able to anticipate needs, whereas when parents felt

that professionals did not empathise there were more likely to be unmet needs and parents felt disillusioned and uncertain (Ryan & Quinlan, 2018).

1.3.3 Barriers and areas for improvement

In any service there are always areas for improvement or barriers that can prevent the service being utilised in the most efficient manner. Family centred care is no different. This section reviews the literature focused on family perspectives on areas where clinical practice could be developed and on barriers to the successful implementation of family centred care as reported by families and professionals.

Areas needed to be improved in an Australian based family centred service centre were examined in a study by Dyke, Buttigieg, Blackmore, and Ghose (2006). They found that family centred care is based on respect, recognition and willingness to build on strengths. However, there were areas which needed further development. These areas tended to centre around the lack of information sharing and the need to provide support families above simply providing therapy. They found that more general written and progress information was needed as well as informing families around therapy options. Continuity of care was another issue that was raised through this study as well as providing general support (Dyke et al., 2006).

A literature review of parents' and health professionals' perceptions of family centred care in hospitals in both developed and developing countries was conducted by Foster et al. (2010). Four main themes emerged being; communication, roles and relationships, caring for parents, and resources. Appropriate communication was seen to be a vital factor, although the level of importance varied depending on the role, situation, and context. When it came to roles and relationships there was a need for relationships to be nurtured, and roles to be negotiated as parents can feel as if their role is usurped by medical staff. There was a need for support for parents as they also had needs that could depend on the environment. Eagerness from medical staff to provide support to families was often present, but a lack of resources, such as time, was a common barrier to this. Parents' available resources also needed to be considered as they may wish to be present, but their degree of involvement differed. A symbiotic relationship

between these four themes was suggested by Foster et al. (2010) as a way of ensuring that family centred care was beneficial to all families regardless of culture, illness severity, or role. A common theme of a lack of knowledge or resources was reported throughout the literature that resulted in non-coherent modes of family centred practice.

Icelandic parents' perspectives of occupational and physical therapy for their children were examined by Egilson (2011) who found that there was a need for communication. Parents were finding that their needs and concerns were more likely to be addressed or considered if they were similar to the therapist's views. There was a need for greater collaboration not just with parents, but also with schools and other professionals, as parents were often feeling like they had the uncomfortable role of being the middle man between the therapist and the school. Parents saw the need for more follow-up of how assistive devices were working, especially once their children started school, and whether therapy goals were transferring into everyday life. Difficulties with collaboration of services and collaboration with parents, especially in school settings have be described over the literature, with the school environment being mentioned as a barrier to family centred care(Mandak & Light, 2018b; Sugden et al., 2017; Tambyraja et al., 2017). Parents also wanted more information and for the therapist to take the initiative when offering information, so that parents were able to make informed decisions (Egilson, 2011). Practical advice, rather than just therapy plans was also important. Utilization of the existing resources of parental expertise, knowledge and support was suggested by James and Chard (2010), as these are often not incorporated into therapy as much as they could be.

It has been shown in the literature that while professionals can profess to have family centred ideals and models of service delivery, but the reality can be quite different (e.g. Dempsey & Keen, 2008; Dunst, 2002; Mandak & Light, 2018b). As seen in the previous sections there are practices and ways of thinking and working with parents and family that promote family centred care. These include valuing parental knowledge and expertise, sharing information, clear communication, and understanding that families' abilities and wishes surrounding their involvement can change over time (e.g. Jasmin et al., 2018; Marshall & Goldbart, 2008; McNeilly et al., 2017; Shields et al., 2012). However, there are also barriers to providing a family centred approach to service delivery.

There are many studies looking at various groups of parents and their experiences with family centred care, but what happens when parents are not being listened to? Lundeby and Tøssebro (2008) undertook to investigate this. A critical prerequisite to listening to parents is having the mindset that parents' views and opinions are important. Therefore, if parents' knowledge is not valued, there seems little point to listening to them, if there is already a mindset of the professional knowing best. There were several areas where parents' concerns and needs were being disregarded. These included during the process of diagnosis, in regards to funding, in issues of jurisdiction, and how different people's knowledge was valued   Parents found that their knowledge of their child tended to be listened to more often in regards to the home environment, although this was not always the case, but when the environment in question changed, so did the reception to parents' knowledge for the worse. Defining the causation of a certain behaviour or issue needs to be a multifaceted process that involves parents. Lundeby and Tøssebro (2008) expressed concern that by not valuing and acknowledging parents' knowledge and views, it may be perceived by parents that their competence as a parent is not being recognized.

Parents feeling like they have to participate in their child's care over what they are expecting or are able to, or feeling like professionals are presuming that they will be involved regardless of their feelings are significant barriers to family centred care (Shields et al., 2006; Shields et al., 2012). There are family, workplace and professional barriers to family centred care (McAllister, McCormack, McLeod, & Harrison, 2011; Watts Pappas & McLeod, 2008b; Watts Pappas et al., 2008). Some of these barriers include lack of time on behalf of both the speech-language therapist and parent, both parent and speech-language therapist beliefs regarding parental involvement, and a lack of speech-language therapist confidence in involving parents (Mandak & Light, 2018b; Watts Pappas et al., 2008). Other barriers include the accessibility of the services available, overreliance on parents, lack or breakdown of communication, not being listened to, and a lack of support during critical periods (Band et al., 2002; Carroll, 2010; Cooper-Duffy & Eaker, 2017; Coyne, 2015; Glogowska & Campbell, 2000; James & Chard, 2010; Lindsay & Dockrell, 2004; Lundeby & Tøssebro, 2008; Lyons et al., 2010; Marshall et al., 2007; McAllister et al., 2011). School settings can also be barriers to parental involvement in

therapy, as many parents are unable to meet with speech-language therapists during school hours (Mandak & Light, 2018b; Sugden et al., 2017; Tambyraja et al., 2017). If parents believe that their children are not valued by the professionals, they may not implement recommendations (Cooper-Duffy & Eaker, 2017).

Lack of time can result in therapy that is therapist driven as this approach can take less time for the speech-language therapist, however as the family may not really be involved, generalisation can be difficult or limited as the family can often be the main communication partner (Iacono & Cameron, 2009; Mandak & Light, 2018b).

1.4 New Zealand context

Family centred care has been part of the New Zealand health context for over 50 years. The development of family centred care in New Zealand between 1960 and 1990 was examined by Chenery (2001). Interviews with mothers who had children hospitalised during this period and nursing staff from the same time period were conducted to combine both professional rhetoric and reality with the parents' perspective. A mother who had a child hospitalised during the 1960's, spoke of very rigid visiting rules and having to invent ways to circumvent them in order for her other children to see her son. She also remembered that there was no acknowledgement from hospital staff regarding the sheer effort she was going to in order to stay connected with her son. Another mother, whose child was in hospital for an extended period of time in the 1980's, expected to stay in hospital with her child and was able to do this and to be involved in a manner in her child's care, but she felt that she had to join in because otherwise she would not know what was happening (Chenery, 2001).

Foster and Whitehead (2017) examined family centred care in a paediatric high dependency unit in New Zealand and found that family is an important part of the New Zealand culture and care. When looking at the Māori health model, Te Whare Tapa Whā, involving the family is very important (Ministry of Health, 2017). Taha whānau (family health) is one of the four dimensions of Te Whare Tapa Whā and it is concerned with involving whānau in healthcare and realising how important whānau is (Ministry

of Health, 2017). Even for families that are not Māori, whānau is still very important and involving whānau can be a vital component of family centred care in New Zealand (Foster & Whitehead, 2017).

Today family centred care is a philosophy and practice that is part of health strategies, however the reality can still be more focused on the child rather than the family (Foster & Whitehead, 2017; Minister of Health, 2016; Ministry of Health, 2017). Involving families in speech-language therapy practices links the three overarching principles of the Te Tiriti o Waitangi (Treaty of Waitangi). These three principles are Partnership, Participation, and Protection. In order for parents to fully participate in therapy, the speech-language therapist needs to work in partnership with them so that parents' expectations and goals for their children are protected. The national body for speech-language therapists in New Zealand, the New Zealand Speech-language Therapists Association (NZSTA), has several values around involving family. These including working in partnership and being person and whānau centred (New Zealand Speech-language Therapists' Association, 2017). The Ministry of Education's Special Education service also works with families to achieve the whānau's goals (Ministry of Education, 2018).

Research to date on family centred care and on parental perspectives of support services for their children in New Zealand is limited, and there is no research examining parental perspectives of speech-language therapy services. Therefore, there is a need to determine what New Zealand parents' perspectives of their children's speech-language therapy are.

1.5 Study rationale and research questions

Knowing that communication between speech-language therapists and parents is essential to ensure that not only good relationships are built but that parental expectations are known and considered does not mean that it is actually occurring. Given such knowledge plus the fact that there is no research looking at this topic in New Zealand, this study aims to investigate parents' expectations of speech-language therapy in New Zealand. The study also investigated how parental expectations are incorporated or not into the therapy process. The specific research questions are:

- What are New Zealand parents' expectations of speech-language therapy for their child?

- Do these expectations change during the therapy process?

- Are parents' expectations being met during the therapy process?

- Are there any additional factors that may help facilitate or hinder the meeting of parental expectations?

2. Method

2.1 Ethical considerations

An application was made to the University of Canterbury Human Ethics Committee. The study was approved in July 2017 (Appendix A). Study information and participant consent were built into the online survey, with respondents unable to complete the survey unless they indicated their consent to participate. Prior to interviews, participants were emailed the study information sheets which were presented to and discussed with participants at the beginning of the interviews. Participants were then asked to complete a consent form. The consent form included acknowledgment that the interview would be audio-recorded. During the interviews, the researcher paid attention to the participants' emotional state to ensure that the interview could be paused or stopped if needed. The researcher had contact information for various speech-language therapy services and counselling services if the participants required them. Following transcription of the interviews, the transcripts were returned to the respective participants for member checking.

2.2 Participants

Participants recruited for this study were parents of children who had received speech-language therapy services in New Zealand in the previous 12 months, or who were currently receiving speech-language therapy services. They were recruited with the support of speech-language therapists and from social media channels. Two speech-language therapy clinics made the study information available to parents. One speech-language therapy clinic was a private clinic and the other clinic was a University clinic. Other parents were recruited via Facebook and University of Canterbury staff and student blogs. Facebook was used as a recruitment method as it allowed for more widespread recruitment as people were asked to share the information with others. The researcher shared the study information and survey link on her personal Facebook page as well as contacting various parents' groups on Facebook in order to contact a wider range of parents. Respondents were recruited to complete an online survey (Appendix B). A total of 23 respondents responded to the initial information and 17 of these went on to complete the survey. Respondents who indicated that they lived in Canterbury were invited to take part in a

follow-up interview. Prospective interview participants were contacted via email and sent a copy of the interview information and consent form (Appendix C) and asked to respond if they were still interested and available. Of the 13 participants from Canterbury, 8 participants were interested in taking part in an interview and so were contacted. Four of these participants then consented to participate in a face-to-face interview.

2.3 Survey

An online survey was developed by creating questions that focused on the research questions and was based on previous research. The survey questions were discussed between the researcher and supervisor. An initial list of questions was also presented to 10 practicing speech-language pathologists for confirmation, addition, and editing to ensure relevancy and appropriateness. The final survey consisted of 24 questions. Questions sought information about:

- Participant demographics (questions 3-11). For example – Age at beginning speech-language therapy (Appendix D)

- Expectations for speech-language therapy (questions 12-15). For example – I expected to be involved with the planning of my child's speech-language therapy (Appendix D)

- Experiences of speech-language therapy (questions 16-26). For example – I understood the focus of my child's speech-language therapy (Appendix D)

Not all questions were presented to all respondents as some questions relied on an affirmative answer to a previous question. An example of this is when respondents were asked if their child could speak any other language fluently, and if they answered yes, a future question was presented asking them what these languages were. To ensure that respondents' understanding of the word "fluently" was uniform a definition was provided, as being able to hold a conversation. The list of survey questions is included (Appendix D). There were a variety of question types, such as multiple choice, selecting an option from a list, Likert-type responses on a scale of 1-7 (from strongly agree to strongly disagree), and questions that required a written response. With the Likert-type questions there was also a further option of not applicable.

Five additional optional questions relating to registering interest in entering the prize draw for $30 of petrol vouchers, participating in an interview, and registering interest in receiving a summary of the results. All questions, apart from the consent questions, were optional and did not require a response to be given order to continue the survey.

The survey was hosted online using the University of Canterbury Qualtrics survey portal (Qualtrics, 2018). Upon opening the survey, respondents were presented with the study information and asked for their consent to participate in the study. The actual consent form was on the following page where respondents were asked to indicate their consent by selecting a series of boxes. If respondents did not select all the consent questions, and attempted to go to the next question, they were prompted to complete the question. This meant that if a potential participant did not give consent, they were unable to answer any further questions.

The survey was pilot-tested by three people who had children who had participated speech-language therapy over one year previous and were not eligible to participate in the study. The only changes that occurred as a result of this testing was correction of minor spelling errors. Test respondents reported that survey questions and functionality were appropriate.

2.4 Interviews

Interviews were conducted with four survey participants. These interviews were conducted in a range of locations. Two were held in meeting rooms in University of Canterbury libraries, one in a clinic at the Department of Communication Disorders, and one was conducted in a participant's home. The interviews were audio recorded using an Olympus WS-812 digital voice recorder. The interview followed a semi structured approach with a common list of questions (Appendix E) for each interview, however the interviewer was free to ask the questions in any order and to ask any additional questions or follow up on any of the participants' responses.

2.5 Data analysis

2.5.1   Survey

The complete responses from the survey were collated in Qualtrics and transferred into a Microsoft Office Excel file. The demographic questions were collated to describe respondents (questions 3-11 – Appendix D). The Likert-type questions and the questions requiring Yes, No, or Maybe responses were analysed using descriptive statistics (questions 12-19 and 21-24 – Appendix D). The questions that required an open-ended written response that were not related to participant demographics were analysed and coded for themes along with the interview responses. The responses to these questions had had all identifying information, such as people's names, removed and replaced with pseudonyms or non-identifying titles (e.g. "therapist" or "child"). Respondents were referred to as "SP1" survey participant one and interview participants were referred to as "IP1" interview participant one.

Questions 12-15, 18-19, and 21-24 of the survey (Appendix D) required respondents to rate how strongly they agreed with each statement on a 7-point Likert-type scale ranging from 'strongly agree' to 'strongly disagree'. In order to analyse this data, the responses were converted numerically and coded as follows; 1 = strongly agree, 2 = agree, 3 = somewhat agree, 4 = neither agree or disagree, 5 = somewhat disagree, 6 = disagree, and 7 = strongly disagree. Percentages were rounded to two significant figures for consistency, which may mean that the total percentages reported for one question could exceed 100%.

The survey questions were divided into two groups. The first group of questions focused on parent expectations (see Table 1) and the second group focused on parent experiences (see Table 2).

Table 1: Questions related to Parents' expectations

Question No.	Parent expectations questions
12.	I expected to be involved with my child's speech-language therapy
13.	I expected to be involved with the planning of my child's speech-language therapy
14.	I expected to be given home practice / homework to do with my child
15.	I expected to learn strategies to help my child

Table 2: Questions related to Parents' experiences

Question No.	Questions about parents' experiences
16.	I was involved in the planning of my child's speech-language therapy
17.	I was given home practice / homework do to with my child
18.	I understood the home practice / homework
19.	Were your original expectations for your child's speech-language therapy met?
21.	I felt like the therapist understood what I wanted my child to achieve from the speech-language therapy.
22.	I understood the focus of my child's speech-language therapy.
23.	I felt that the therapist was able to adjust the speech-language therapy to fit my child and our family.
24.	I understood what was going to happen at the end of my child's speech-language therapy.

The remaining questions were analysed and coded for themes using thematic analysis (see Table 3). The last question that was coded for themes was not completed by all respondents as shown in Table 3. This was to be expected because the question was a request for any further information that the respondents felt to share. The codes that these survey questions produced were combined with the

interview themes as there are only limited codes from the survey questions which would not support a thorough thematic analysis on their own.

Table 3: Survey questions and response numbers

Question No.	Survey question	No. of Responses
20.	How did your expectations for your child's speech-language therapy change?	17
25.	The things that I most wanted to happen as a result of the speech-language therapy were?	17
26.	Any other information or thoughts you would like to share?	11

2.5.2   *Interviews*

The interviews were transcribed verbatim, checked against the audio recordings for accuracy and then returned to the participants for member checking. Member checking is used to ensure accuracy of the data and to allow participants to change or remove any data that is inaccurate or that they do not want to be included (Portney & Watkins, 2008). Member checking also allows participants to add any further information that they feel would be beneficial at this stage.

After member checking was completed, transcripts had all identifying information, such as people's names, removed and replaced with appropriate titles (i.e. "child" or "IP1" etc). Some participants opted to clarify some of their responses by removing extraneous words.

The interview transcripts were analysed using thematic analysis.

2.5.3   *Thematic analysis*

The three questions from the survey discussed above (see Table 3) and the interview transcripts were analysed using thematic analysis. This was done by utilising the suggested framework in Braun and

Clarke (2006). Thematic analysis is a qualitative analytic method for "identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79).

The researcher began by familiarising herself with the data. The process began with transcribing the transcripts and was continued by reading the transcripts several times. This was done to allow for a thorough knowledge of the content of the data. Initial notes were made during this process of interesting or potentially significant areas.

All the data was then examined, and initial codes were developed. A list of codes used was kept ensuring that the codes were consistent across the data. The transcripts were examined several times to allow for all possible aspects of the data to be coded. The codes were then grouped into themes. The themes were then reviewed considering all the data to refine each theme and to ensure that the data linked with the themes.

3. Results

New Zealand parents of children who had received speech-language therapy in the last year were asked to complete a survey regarding their expectations and experiences. 17 parents completed the survey. Four participants then completed a semi-structured interview. The data collected provided a range of insights into parents' experiences and perspectives of speech-language therapy services. This section reports the demographic information of all participants, survey findings and themes identified from data reported by the interview participants. Example quotations from data provided by participants are provided to support the identified themes.

3.1 Demographic information

3.1.1 Survey demographic information

Twenty-three respondents commenced the survey. However only 17 respondents fully completed it. All incomplete survey responses did not proceed beyond the first question, so they were excluded from analysis, leaving 17 responses for analysis. Demographic information related to the children of respondents indicated that there were six female and 11 male children. The average age of children at the beginning of their speech-language therapy was 4 years 9 months with a range of 2:5 to 10:0 years. The respondents were mainly from Canterbury ($n = 13$) with other regions of New Zealand also represented ($n = 4$) (see
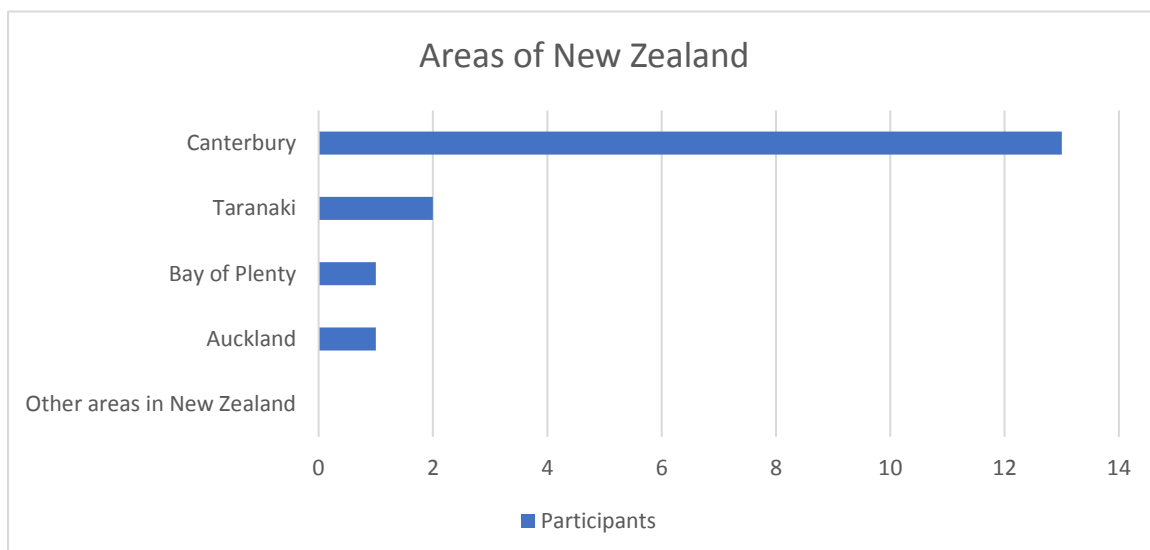
Figure 1).
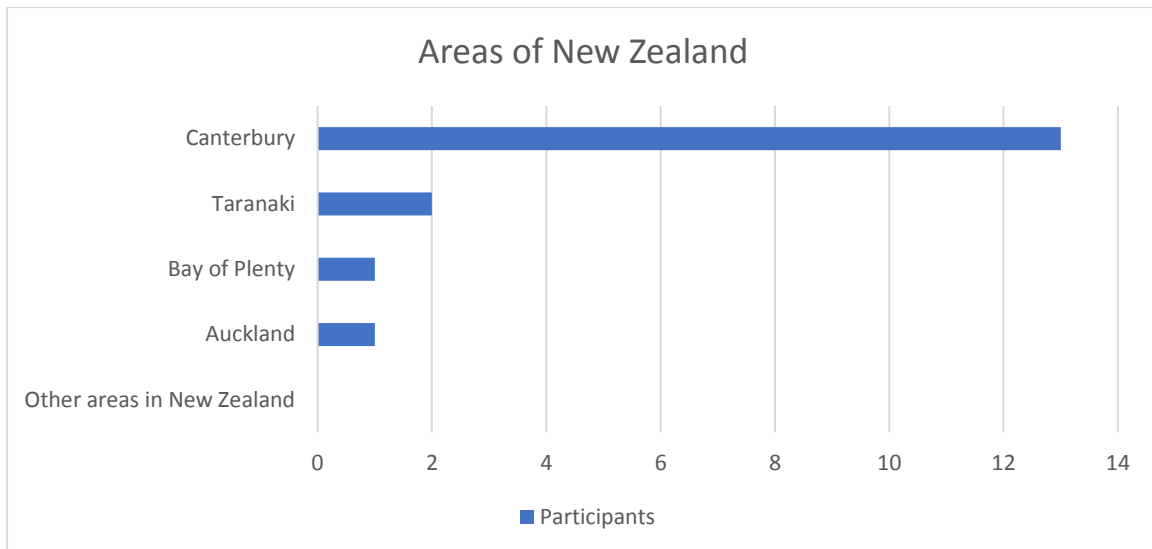
Figure 1: Geographical spread of respondents

All respondents reported that their child's first language was English, although two noted that their children had heard Tagalog along with English for their first year or two of life. One participant reported that their child also spoke French. The majority of the children were receiving speech-language therapy services because their speech was not sufficiently intelligible. The length of time respondents had been involved in speech-language therapy support for their children varied from two sessions to six years. Five children were receiving ongoing therapy without any foreseeable discharge plans. A breakdown of specific service providers respondents accessed is provided in
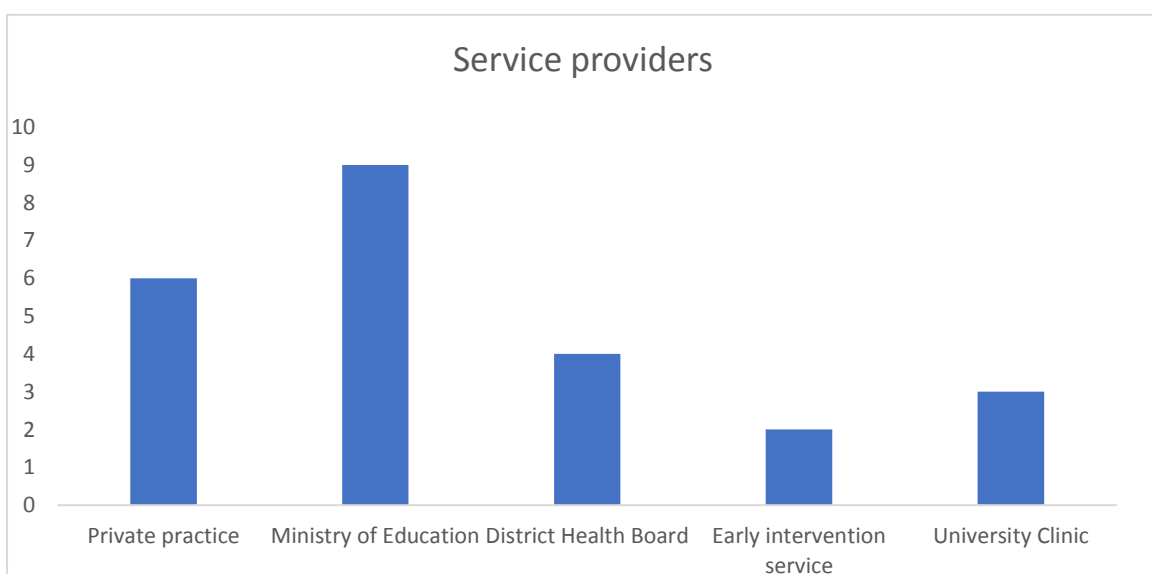
Figure 2.
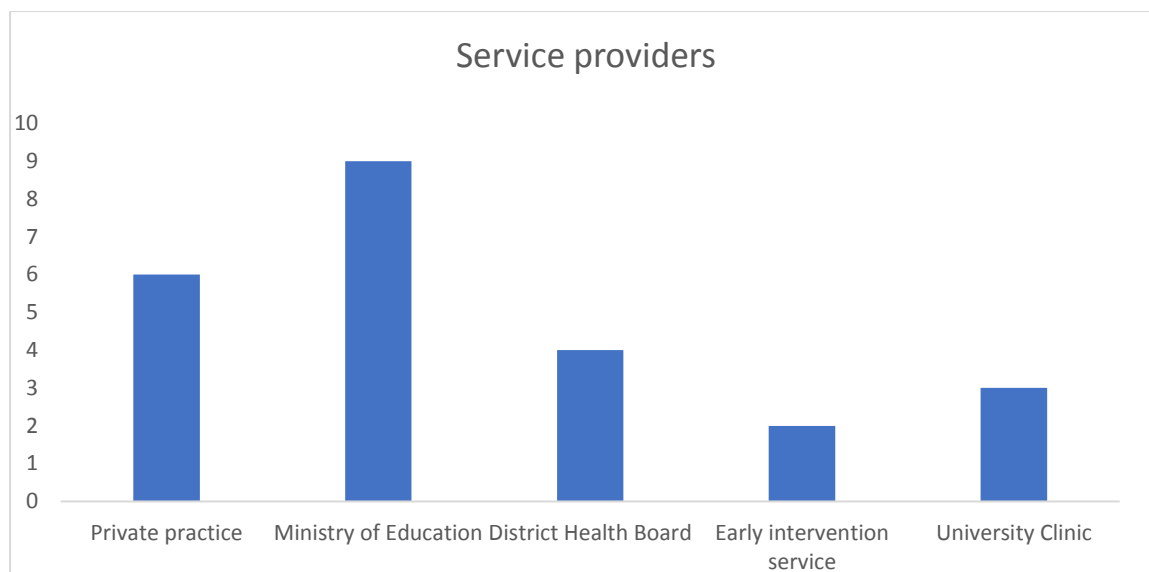
Figure 2: Service providers

Three respondents accessed two different service providers and two respondents accessed three different service providers. One respondent reported that their child had previously had speech-language therapy overseas some years ago before she began speech-language therapy in New Zealand.

3.1.2   *Interview participant demographic information*

The four parents (mothers) who participated in the face-to-face interviews were parents to three male children and one female child. The four interview participants' children had a mean age of 4 years and a range of 2;5 to 8;0 when they began speech-language therapy in New Zealand. Three of the four children either spoke another language as well as English or had been exposed to another language for an extended period of time. The majority of the participants received speech-language therapy for reasons connected to unintelligible or unclear speech. The children had been receiving speech-language therapy services for an average of 1;7 years with a range of 1 to 3 years. Two of the children were still receiving speech-language therapy services. There were a range of service providers being accessed. These included University clinic ($n = 1$), Ministry of Education ($n = 3$) and a private clinic ($n = 1$). One participant was receiving a combination of services from both the Ministry of Education and a private therapist. Two of the participants were in primary school by the end of their therapy and the others had yet to begin school.

3.2 *Survey results*

The survey results that follow are divided into expectations and experiences. For some of the questions, the number of responses (*n*) is less than the total number of respondents because some of the questions depended on a particular response to an earlier question. For example, question number 18, which is about parents' experiences with home practice requires respondents to have answered 'yes' to an earlier question.

3.2.1   *Parents' expectations*

The questions that relate to parents' expectations consist of 4 statements. They are:

12. I expected to be involved in my child's speech-language therapy

13. I expected to be involved with the planning of my child's speech-language therapy

14. I expected to be given home practice/homework to do with my child

15. I expected to learn strategies to help my child

The majority of respondents rated their level of agreement with these four statements between 1-3 (Strongly Agree to Somewhat Agree). For statement 12, 94% of respondents (*n* = 16) responded 1, 2, or 3, for statement 13, 82% (*n* = 14), for statement 14, 100% (*n* = 17), and for statement 15, it was 82% of respondents (*n* = 14).

3.2.2   *Parents' experiences*

There were eight questions relating to parents' experiences (see Appendix D). Some questions linked with previous questions about parents' expectations and one was similar to the parents' expectations question in the case that it was a list of statements (see Table 2 for the list of the questions).

Responses to questions 16-19 and 21-24, suggested that parents had a range of experiences regarding speech-language therapy for their children. Forty seven percent (*n* = 8) reported being involved in the

planning of their child's speech-language therapy. This was contrasted with 47% ($n = 8$) who were not involved, and one parent was unsure as to whether they were involved or not. Question 17 asked parents if they were given home practice to do with their child. Sixty five percent ($n = 11$) were given home practice, with another 24% ($n = 4$) being given home practice sometimes and 12% ($n = 2$) were not given any home practice. The 15 parents who answered "yes" or "sometimes" to the home practice question were then asked to rate on a 7-point scale how well they understood this. Thirteen (87%) of respondents either strongly agreed or agreed with the statement.

Question 19 asked parents to rate how their original expectations were met. A variety of response were noted (see Table 4 for a summary of their responses).

Table 4: Meeting of original expectations

Response option	Number of responses	Percentages
Strongly agree (1)	1	5.9%
Agree (2)	7	41%
Somewhat agree (3)	2	12%
Neither agree or disagree (4)	1	5.9%
Somewhat disagree (5)	2	12%
Disagree (6)	1	5.9%
Strongly disagree (7)	3	18%

Ten (59%) of respondents' answers were between 1-3 showing that they agreed that their original expectations were met to some extent. However, 36% ($n = 6$) of respondents indicated that their original expectations were not met to some degree.

Question 21 asked respondents to rate how well they perceived that the therapist understood what they wanted their child to achieve from speech-language therapy. Fifteen (88%) respondents indicated agreement with ratings between 1-3, while 12% ($n = 2$) of respondents rated their disagreement with ratings of 5-7. Respondents were asked to rate their level of understanding of the focus of the speech-

language therapy in question 22. Fifteen (88%) respondents rated their agreement with the question, between 1-3, while 5.9% ($n = 1$) rated it a 4 and 5.9% ($n = 1$) rated their level of disagreement a 6. Respondents were also asked to rate how they felt the therapist adjusted the speech-language therapy to fit their child and family (question 23). Seventy one percent ($n = 12$) of respondents rated their experience of this between 1-3, while 30% ($n = 5$) of respondents rated their experience more negatively. In question 24, respondents were asked to rate how well they understood what was going to happen at the end of their child's speech-language therapy. One participant marked this question non-applicable for them, so they are not included in the analysis of this question. Eight (50%) respondents indicated that their understanding was between 1-3, 19% ($n = 3$) rated their level of understanding a 4, and 32% ($n = 5$) of respondents rated their level of understanding between 5-6.

3.3 Thematic analysis of survey and interview data

All responses to the open-ended questions in the survey (see Table 3) were collated along with the coded interview transcripts. A thematic analysis identified five overarching themes and 14 subthemes related to the expectations and experiences of parents. These themes and subthemes are:

- Expectations
    - Expectations for therapy
    - Look of therapy
- Working as a team
    - Fitting therapy to the child
    - Focus
    - Partnership
- Funding
- Important aspects of therapy
    - Consistency
    - Home practice
    - School

- Considerations
  - o Additional referrals
  - o Early intervention
  - o Information for speech-language therapists
  - o Information gathering
  - o Motivation for therapy
  - o Results of therapy

Each of these themes and subthemes are presented below together with supporting examples from participants' data.

3.3.1 Theme 1: Expectations

The theme expectations encompass two sub themes. These are; expectations for therapy and look of therapy.

3.3.1.1 Expectations for therapy

Parents expected that their children would be able to communicate better as a result of the speech-language therapy.

> *The key things that we were after from them was that when he started school he would be ready. And that he wouldn't end up wasting his first year, because he couldn't communicate properly. (IP2)[1]*

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[1] Deidentified participant codes are provided after quotes to preserve anonymity. For example, respondents with 'SP' before the number refer to survey respondents only and participants with 'IP' before the number refer to participants who completed both the survey and interview.

> *That my child could express himself to others, and engage in conversation, expressing himself sufficiently. (SP2)*

Parents were also expecting increases in their child's confidence and self-esteem. They expressed hope that their child's increased speech and language skills would help their child socially. For example, participant parents stated:

> *I wanted him to achieve confidence around speaking, able to pronounce words properly and have healthy communication and relationships. (SP7)*

> *For my son to have clearer speech and as a result have a higher self-esteem due to him being understood better both in the classroom and by his peers. (SP4)*

Speech-language therapy was not see as a magic cure by some parents, they recognised that they would have to put in work in order for their child to change.

> *So, it's pretty much what I expected. I expected that most of the work would be done by us and she would just be guiding us and telling us what to do. (IP3)*

> *3.3.1.2 Look of therapy*

Parents reported that when therapy began it did not look like what they were expecting.

> *That they would work with him, where it was more focused on educating the parents. (IP2)*

> *It was very very different. It was very play based. (IP1)*

Other parents had very little expectations for what therapy would look like.

> *I had never experienced speech-language therapy therefore had few expectations beyond my involvement and ongoing participation. (SP2)*

> *No, I had no idea what it would be like. (IP2)*

Some parents had expectations as to what therapy would look like based on their qualifications.

I have a degree where I majored in linguistics so that gave me some idea of how they might approach it, but it was completely different to how I thought it was going to be. (IP1)

3.3.2 Theme 2: Working as a team

This theme had three sub themes that were; fitting therapy to the child, focus, and working together.

3.3.2.1 Fitting therapy to the child

Parent found that when the speech-language therapy suited their child rather than their child having to fit to the speech-language therapy, they felt happier with the speech-language therapy.

They just accommodated a little boy whose personality is completely out of the box [laughter], he's a guy who lights up a room everywhere he goes, but they managed to keep him on task and on track in a fashion that really interested him. (IP1)

I have two boys, both have received speech-language therapy. My first son was engaged very well by the therapist, who brought games and toys for rewards after the practice exercises. My second son was present during these sessions and was very disappointed when this reward technique was abandoned. He did not engage as well in the therapy and is behind where his brother's progress was at a similar time in therapy. (SP2)

Whereas when parents felt that when the speech-language therapy was not fitted to the child or that the speech-language therapist did not understand where the child was, therapy was much more difficult, progress was harder to see, and their child did not enjoy the speech-language therapy.

The SLT failed to understand the impact a brain infection had had, she moved too quickly through each concept she was teaching despite being warned that in the past ideas would be achieved in one session and forgotten in the next. Child was unengaged and refused to participate; SLT didn't change approach, just pushed back and said it was just because it was hard. (SP15)

The thing that has surprised me is there's not much variation. So, every time we are seen we change the sound, but the methods are all the same. And it, there was a while where he was just like "I don't want to do this anymore, this is too boring". (IP3)

Parents also felt that the speech-language therapy needed to not just be tailored to their child, but also to their family.

So, I think that's really important to see, yeah, where the child and the parent is at. (IP4)

She's, so this is the private one that I've had, I think's got a really good grasp of where she's at and she's actually been really good in that sense. So, she hasn't pushed the using strategies when she wasn't ready for it. (IP4)

3.3.2.2 Focus

This sub theme looks at who parents thought would be the focus of therapy and what actually happened. Some parents felt that the focus would be mainly on the child.

I didn't expect them to work so much with us, the parents. (IP2)

Initially I was kind of thinking shouldn't you be doing some more stuff with him and less with us to get him talking until they actually kind of said their role, particularly as he got a bit older. (IP2)

Other parents expected the focus to be primarily on the parents.

So it's pretty much what I expected. I expected that most of the work would be done by us and she would just be guiding us and telling us what to do. (IP3)

3.3.2.3 Partnership

This subtheme linked with participants reporting feeling valued by the therapist and therapy being a partnership.

I mean it was very partnership based thing. I like the fact that I was involved with what they were doing. (IP1)

When parents perceived that there wasn't enough communication occurring they were concerned and didn't necessarily understand the reasoning underlying certain decisions.

> *And, it was an email conversation followed up by a phone call on how he was doing and that prompted the decision by the Ministry to end the speech therapy … And that they would have assessed him before they made that decision, not based it on what I said. And so that's something I thought, the way in which they sort of concluded the therapy didn't seem quite right to me. (IP2)*

Parents also wanted ideas on how they could "do" therapy at home.

> *But also, she's the one with the knowledge and experience of trying to make kids say stuff so maybe she's this knowledge and of bank of games that might work. Yes, we know our kid best, but you know some of those other ideas might be good. (IP3)*

Parents also found that there didn't always seem to be enough discussion around what resources the family had available, e.g. time.

> *Realising that the parents are the ones who are spending the most time with the child so very much respecting their view and their position and the time in which they have to commit to assisting their child and then formulating exercises and whatever you are giving the family to do around how much time the parents actually have. Because that was not something that was ever asked. (IP2)*

3.3.3   Theme 3: Funding

This theme of funding or 'who pays' for speech-language therapy related to how parents saw funding affecting therapy and their child, ideas on how parents thought that funding could be more extensive or how they saw that funding could be applied, and how parents reacted to having funding in place (or not).

When parents were able to access publicly funded speech-language therapy, they were appreciative.

> *I think it's amazing that it is funded. (IP2)*

However, when parents were unable to access publicly funded speech-language therapy and the cost of private speech-language therapy was too much for them, they became frustrated with the system.

> *There is great frustration with the lack of speech therapy services. Not eligible for very much other than private speech therapy which is not obtainable for our income level. Very little support from MOE and none from hospital board. (SP17)*

Parents also found that accessing funding could be difficult.

> *So that was actually the difficult thing that I had to go get private therapy to get into the Ministry, so I don't know how people get into it otherwise when you've got preschoolers. (IP4)*

Parents were very aware of what speech-language therapy could do and has done for their children, and how publicly funded speech-language therapy has or has not made that possible.

> *I'm really glad that it is funded, and we've not have to have any issues with that so just for wellbeing. I guess it effects people's self-esteem even if it's much more minor. Especially for the major stuff, I'm just very thankful that it's funded. (IP3)*

> *I had been asking for help since my son was three. He had an initial assessment at CDHB and ENT assessment and treatment. We were told he had a tight voicebox and needed to treat it. We were referred to Special Education, yet told by Special Education that speech was not severe enough for therapy by them. I expected to have more help from Special Ed, but they were willing to pick him up for behaviour and learning. My expectations changed because I believed he wasn't severe enough for the help. However, 3 years later when we experienced 2 school expulsions by the age of 6, Whakatata House offered Speech Language therapy and told us they were surprised he had not received SLT [speech-language therapy] before this time. I expected that despite his behaviour and anxiety we would receive sessions with Whakatata House. (SP7)*

Parents had some different ideas about how they could see publicly funded speech-language therapy being more extensive.

So, I think in an ideal world, publicly funded speech therapy for as many kids who need it. (IP2)

So, if the government could go half and half, we're not this is not a commitment for the government for child or for many other children I would think for the rest of their schooling life, it's for a very short period. So, if you have got a diagnosis from accredited professionals I think you should be able to say that we've got this we'll fund a third of it or we'll fund half of it for this amount of time. (IP1)

3.3.4   Theme 4: Important aspects of therapy

This theme was highlighted by participants' comments about aspects of therapy that they found particularly important. Important aspects of therapy had three sub themes which were: consistency, home practice, and school.

3.3.4.1 Consistency

Parents valued consistency of therapists and even chose to stay with a therapist they were not completely happy with because their child had a good relationship with the therapist.

It's good that there's never a substitute or yeah. So, I am kind of keen to continue just with the same person, but you know, maybe another person would be better, and it would work out fine, but yeah, continuity is quite important for us. (IP3)

Having the same day and time for each session was preferable for parents.

Maybe it being more regular at certain stages. So, you know if it was always every fortnight or every three weeks. We just knew it was always like that it might be good cos sometimes we end up missing, might not have it for a month or five weeks or, you know, because our schedules clash. And it's good that we can be flexible and she's like "when suits you", and we can find a good time; she comes to me which is the most amazing thing ever. But, um you know also having a certain time slot for every single time might just help a bit. (IP3)

And the consistency, the fact that it was the same time every week. (IP1)

When the therapy was being delivered by different therapists, having a consistent supervisor was valued.

The people were always different, but the supervisor was always the same. And I think possibly she kept a cohesive strand going through. (IP1)

3.3.4.2 Home practice

Parents reported that doing the practice at home could be challenging.

I guess in the initial stages I found it really hard to put anything into practice. (IP4)

Parents also found that their child was happy to do the work with the speech-language therapist, but after the speech-language therapist left, it became difficult.

He really likes her and so he does look forward to her coming, even though sometimes what she makes him do is hard. He's more keen to practice with her than he can be with us. And if, you know, sometimes there'll be a game or, you know, at the moment he's quite into bingo so he's quite enthusiastic about that and will sometimes want to play with his brother and sister. But in general, he's more happy to practice when she's there than when she's not. (IP3)

In order to counter this, parents often had to come up with different ways of doing the home practice.

And he would practice the exercises while they were there, and he would do them. As soon as I tried to do them after they left, it was like "nah, not interested Mum". So, I had to develop techniques to fit the exercises into everyday activities. We couldn't sit down and use the flashcards or anything that they had given us, because he just thought that was hilarious and wouldn't do it. So, I had to actually create all these other ways of doing the exercises with him. (IP2)

3.3.4.3 School

This sub theme has two parts. One part is related to how important school involvement is and the other part is related to what parents want for their child to be able to do at school relating to their speech and language abilities.

Parents overall had good experiences with their child's school's involvement in their child's speech-language therapy, but they noted how this could have been much more difficult if the school was not on board.

> *They said, "what else could we do?" So, he had touch typing lessons and that was all attended to very quickly and when I said about speech therapy they said, "there's no way we can get funding for that, we can give you the time off for him to go, you're welcome to take him any time but we can't get funding for that". (IP1)*

> *The school was very good at communicating with us about what was going on, but I could see that for other parents if the school wasn't so good you actually wouldn't really know what was going on all the time. (IP2)*

Parents wanted for their children to be able to participate in school and make friends the same as any other child.

> *He is now at a school where half his classmates are Cantonese so it's important that he has clear speech. (IP1)*

> *Have my son be able to communicate comfortably with his peers and teachers. (IP2)*

> *For my son to have clearer speech and as a result have a higher self-esteem due to him being understood better both in the classroom and by his peers. (SP4)*

3.3.5   Theme 5: Considerations

This theme looks at other aspects of the therapy process that perhaps were not completely essential aspects, but ones that the parents still felt important enough to mention. This theme also looks at things that parents would like speech-language therapists to consider. There are six sub themes which are: additional referrals, early intervention, information for speech-language therapists, information gathering, motivation for therapy, and results of therapy.

3.3.5.1 Additional referrals

Additional referrals generated mixed feelings from parents. One parent had a very positive experience with referrals for hearing tests.

> *That was a very fast efficient process, we got to the hearing test quickly, it wasn't like we had to wait for months and that got him through quite fast. (IP1)*

Another parent found that the extra referral for an early intervention teacher was a real barrier.

> *That made that extra referral which we, yeah, we really had an issue with. Might of just been the person who came out, but the sorts of questions that they were asking, the sorts of things they were trying to get us to do, just made me feel really bad as a mother, like I'd forgotten to do a lot of stuff or something.   (IP2)*

3.3.5.2 Early intervention

Parents believed that early intervention was essential to their child's development.

> *This is a huge MUST before children start school to get the support before they turn 5. (SP10)*

3.3.5.3   Information for speech-language therapists

Parents were asked if there was anything that they would like to tell speech-language therapists and they had a variety of insights to share.

> *You can make a really really big difference. (IP1)*

> *I would like to see therapists develop better skills in working with behaviour and difference, because often they go hand in hand with speech issues. (SP7)*

> *The main benefit that I received from our early sessions was the therapist reassuring me that she was developing and pointing out new words/behaviours/abilities that the therapist had noticed since the last session. Reassurance for the parent is extremely helpful and encouraging. (IP4)*

3.3.5.4 Information gathering

Having information about what typical speech-language development was and how their child differed from this was important to parents. Understanding their child's particular condition or what difficulties they were having was also important.

> *I was/am expecting information about typical patterns of language / speech development. (SP16)*

> *For me to understand if there were underlying issues surrounding her abilities. (IP4)*

3.3.5.5 Motivation for therapy

Parents reported regarding the importance of motivation, both for them and for their child. The motivation was sometimes intrinsic, sometimes it was related to wanting to see what would happen next and other times it was the therapist who provided the motivation.

> *But we were motivated to change, child was motivated to change because he knew something wasn't quite right but couldn't quite figure out what it was. (IP1)*

> *And I kept saying to him "you don't want to go back and go backwards do you? Do you really want them to look at you and say, 'oh you're actually not saying that as well as when you left?'" So that was a motivating factor for him. (IP1)*

> *The fact that made it so much fun for him to learn. He really wanted to improve by the next week because he wanted to see what the next step would be. (IP1)*

3.3.5.6 Results of therapy

Parents found that while their main expectation for therapy was that their child's speech and language skills would improve, there were other results or turning points in the speech-language therapy process. For some parents, they found that seeing progress themselves could be difficult, so have the speech-language therapist point out where their child had made progress was helpful.

> *So, it's good to see the progress and then just how much other people understand him more than they used to. Cos that can be hard to judge cos I understand 95% of what he says so. So, it's the people that don't see him so often or and especially strangers. Cos you know everyone gets kind of used to it to some level, but, you know you want him to be able to be understood by other kids and strangers. (IP3)*

> *That's the main thing, having someone pointing out progress is actually really helpful. (IP4)*

Another thing that parents found helpful was learning how to apply strategies to help their children.

> *For us it was useful to have some more appropriate techniques to help him. (IP2)*

> *That's the bit where it was useful that I was being taught that, because then when we were just having everyday conversation, I could slightly tweak whatever he was saying and say, "oh do we say it that way or should we try this way". (IP2)*

Decreasing their child's frustration levels, was a definite positive result of therapy for parents.

> *Because his ability to make friends and ability to make himself understood has been greatly enhanced by this. And he's not as frustrated. He was getting very very frustrated with the fact that kids didn't understand him, they weren't unkind, they just didn't understand him. (IP1)*

Parents also found that the results of therapy were not always what they had hoped for.

> *Believed it would help her confidence, instead led to a drop in her confidence with how she was treated when she felt frustrated. (SP9)*

> *My expectation was we would isolate the issue and work on it. The work took longer and had a less satisfactory long-term result than I hoped. (IP1)*

4. Discussion

This study set out to examine parents' expectations and experiences of speech-language therapy services for their children. The aim was to develop a better understanding of parents' experiences based on the underlying family centred care approach to working with parents (Auert et al., 2012). Four research questions guided the development of this study. Finding related to each research question will be considered below in relation to existing literature.

4.1 What are New Zealand parents' expectations of speech-language therapy for their child?

Parental expectations of the parents in this study were similar to those found throughout the literature. For example, similar to parents in the study by Edwards et al. (2016), the parents in this study expected the speech-language therapy to result in improved children's speech and language skills. Expecting to be involved in planning and therapy processes was another aspect that was similar to previous research (e.g. Auert et al., 2012). Parents also were expecting to be given home practice to do with their child, and to learn strategies to help their child.

Expecting progress is a common expectation of parents for their children (Auert et al., 2012; Lyons et al., 2010). The parents in this study wanted their children to be able to communicate with their peers and family. For preschool aged children, their parents expected that the speech-language therapy would be able to have them ready to communicate easily for school, so they would be able to participate fully. One parent expressed their expectation regarding this.

> *We wanted initially while he was younger to be able to communicate better with us, obviously, and then trying to get him up to a level where he could communicate with his peers ... so that when he started school he would be ready and that he wouldn't end up wasting his first year, because he couldn't communicate properly. (IP2)*

Parents of school aged children wanted their children to be able to communicate with their peers, build friendships, and to be able to participate in school. The parents in this study were aware of the importance of being able to communicate and expected that the speech-language therapy services that they received would be able to target this area.

Parents tended to be unsure as to how the therapy for their child would look, but were more likely to expect the speech-language therapist to work more one-on-one with their child, which can be a common parental expectation (Baxendale et al., 2001). Parents expected to be involved in the entire therapy process, which is a common finding in the research. Parents also relied on their educational background, but this did not necessarily help either as one parent found.

> *I've got a reasonable knowledge of education and it was more play based than I thought it was going to be. (IP1)*

Providing parents with home practice activities to do with their child, is a common way of increasing the amount of therapy that a child receives and can also be seen as involving parents in therapy (Sugden et al., 2017; Watts Pappas et al., 2008). Home practice activities need to be adapted to suit each family and child as this can be an issue for families (Sugden et al., 2017). Families can find home practice activities very challenging to complete with their children and often had to adapt them to interest their children, which was something that they would have appreciated more support with as found one parent.

> *Just the more ideas of ways to keep him engaged, because if he's working on something hard, it's much harder to get him to want to practice and especially in those times it needs to be fun, otherwise he's not going to want to do it and we can't make him. (IP3)*

Parents were also expecting to learn strategies to help their children's communication.

> *I guess just ways, anything I hadn't thought of to improve her language. (IP4)*

Parents are expecting to learn how to help their children and as such, speech-language therapists need to be prepared for this. Parents may not have clearly defined ideas for what their role in their child's speech-language therapy will be, but they know that they want and expect to be involved and to learn how to help their child. Davies et al. (2017) examined parent roles and how they change and suggested that as parents gain knowledge and confidence they may find what they perceive their role to be changing. They also found that parents are expecting to be learners and as such speech-language therapists need to support them in this (Davies et al., 2017). Lyons et al. (2010) also found that parents were expecting to learn how to support their child's communication development.

4.2 Do these expectations change during the therapy process?

Parents' expectations can change over the course of the therapy process. When parents' expectations did change, this tended to be a result of them adjusting to a longer-term view than they had originally expected. This change in expectations may have taken place due to information they received during therapy, with parents becoming aware that their child's difficulty may take more time to resolve than they originally thought.

> *We found out more information about my son's issues, that made me understand it may take some time to work through his issues. (SP13)*

Because this information was given to parents, they were able to adjust their expectations accordingly and were able to see the situation as a positive one, rather than being frustrated that their child's issue was not immediately fixed. Information for parents can help have a positive effect on their environment and can affect their engagement with therapy as they can understand what is happening (Bachner et al., 2006; Robert et al., 2015).

4.3 Are parents' expectations being met during the therapy process?

Over 50% of survey respondents reported that their expectations were met, in some manner, but there remained a substantial portion of the respondents who reported that their expectations remained at least partially unmet. McAllister et al. (2011) found that there was a link between the meeting of parental expectations and the manner in which they viewed their experiences. This was the same in this study. Parents who found that their expectations were met, had positive experiences such as the parent below who was very happy with the service that their child received.

> *We had remarkable therapists. They made beautiful resources, specific to her interests. They let her make choices about games to play during therapy. I'd be happy to tell you anything further. It'd be a rave for MoE [Ministry of Education] we had intermittent therapy over a 2.5yr period and are likely to be discharged at next assessment. We often got a 6-week block then a term off where we continued our daily home practice. Then a term of therapy and few months off etc. That was great for us. (SP13)*

Parents who felt that their expectations were not met, tended to have more negative experiences. For example, one parent found that when their expectations for possible outcomes were not met, and the opposite was occurring they found the experience a negative one.

> *Believed it would help her confidence, instead led to a drop in her confidence with how she was treated when she felt frustrated. (SP9)*

Meeting parental expectations, or at least acknowledging them and educating around them, is an important part of working with parents rather than expecting parents to just fall in with what the speech-language therapist thinks is best for the child. Generally, parents felt that the speech-language therapist understood to some degree what they wanted their child to be able to achieve as a result of the therapy, which suggests that communication is occurring between speech-language therapists and parents. Some parents' expectations were not met, but they understood how other factors did impact on their child's progress and while they were still disappointed that their child had not made the progress they hoped for, they did partially understand why this may have occurred.

> *I think I would have expected to fix the problem, but it didn't. But that is also because the practice needs to happen to change this. (SP14)*

This suggests however that the speech-language therapy may have needed to change in order to support the family better. Whether this would have resulted in more progress is unknown, but in order to help maximise the therapy results the service provided needs to ensure that it is able to change as families' needs change (Hodgetts et al., 2013).

4.4 Are there any additional factors that may help facilitate or hinder the meeting of parental expectations?

The presence of many of the factors discussed in this section have the potential to help facilitate the meeting of parental expectations and the absence of them can have the opposite effect.

A factor that was shown to be important to parents was consistency or continuity of therapy. Having consistent contact with the same professional has been found to allow relationships to be built and for

the child's care to potentially be enhanced as professionals are able to draw on their knowledge of the child and their family (Fereday et al., 2010). Parents value having consistent contact with the same professionals and this is something that can be lacking in various services (Butler et al., 2014; Carroll, 2010; Dyke et al., 2006; Robert et al., 2015). Parents were also willing to stay with a speech-language therapist they were not entirely happy with because it was the same therapist that they had seen for the entirety of their child's speech-language therapy and they did not want to have to introduce a new person.

> *It's good that there's never a substitute or yeah. So, I am kind of keen to continue just with the same person, but you know, maybe another person would be better, and it would work out fine, but yeah, continuity is quite important for us. (IP3)*

Robert et al. (2015) found that continuity was important for parents because having to make new relationships with different professionals could affect both the parent and their child negatively and could be seen as a step backwards. Therefore, consistent therapy from the same person is important to parents.

Speech-language therapy as a partnership was something that greatly enhanced not only the meeting of parental expectations but also their and their child's experience. Because of this, one factor that parents found had the potential to both help and hinder the meeting of parental expectations was how well the therapy was tailored to fit the child and their family. When the therapy matched the child's interests and abilities and suited the family, i.e. ensured that it was not too time consuming for families, families found that therapy was easier and home practice was more likely to be completed.

> *It's important to me that the therapy meets the ability of parents and the child. At the beginning of her therapy we didn't do the practice sessions nearly as much as I would have liked to, however in hindsight this was because it was such a chore as her focus wasn't there and I was extremely time poor. As her focus has developed and she has matured enough for short practice sessions it is much easier and we practice much more frequently. (IP4)*

But when child interests and abilities were not considered adequately, parents found that home practice could be challenging, and it was less likely to be completed. However, parents found that being encouraged and reassured around their child's level of progress was extremely helpful and important.

> *The validation and encouragement for the parent is huge. (IP4)*

Parents need support as well as their child. Supporting parental needs and acknowledging their emotions is important to allow parents to feel that their goals for their child can be realised (Bruns & LaRocco, 2017). Particularly in the early stages of speech-language therapy, where perhaps there was not a lot that parents felt that they could do at home due to the child's attention span or readiness for therapy, speech-language therapist encouragement regarding the progress that their child was making was extremely important.

Early intervention for speech-language difficulties was something that was very important to parents. Parents believed that early intervention should be available when there were difficulties that could impact on their child's ability to learn.

> *This should be a MUST in young children before they reach school, so they are not left behind. (SP10)*

The importance of early intervention is something that parents are aware of and often they will want to start therapy as soon as a problem is realised (Band et al., 2002; Watts Pappas et al., 2016). Parents are wanting their children to be able to start school with as many advantages as possible. They do not want them to 'waste' time once they start school by having to catch up to their peers in areas of communication. When a 'wait and see' approach, i.e. for the parents to wait and see if the difficulty goes away or gets worse, is recommended or utilised, parents are still likely to want the problem or difficulty to be treated as soon as possible (Glogowska & Campbell, 2004). Because of this, care should be taken when a 'wait and see' approach is suggested to fully explain why that particular approach is being used.

Parents felt that there was not enough attention paid to what resources parents had available to devote to their child's treatment.

It was just presumed that because I happened to be at home on the day we had speech therapy, that I potentially didn't work much. And so, yeah, just having expectations of the parents that are realistic of, you know, where they are in life and what they're doing. Yeah. I mean for us, both my husband and I are university educated with one child, reasonably ok financially so we could pour a lot of resource into doing everything he needed to help him with the speech therapy and I think there's a lot of people who are not in that position. (IP2)

Parents often have to balance competing demands on their time and other resources and this is something that can be overlooked by professionals (Hanna & Rodger, 2002). Professionals need to be aware that parental involvement with therapy can vary, which may be a result of daily life occurring. Expressing this, to parents allows them to feel confident that the process with a lesser degree of involvement on their part for a period of time (Marshall & Goldbart, 2008). The service offered may need to change in order to reflect families' abilities to participate as other aspects of their life may take priority for a time and professionals need to recognise this and respond accordingly (Dodd et al., 2009; Hodgetts et al., 2013). Lack of understanding regarding the resources that a family has available, can limit the relationship building between parents and professionals (Dodd et al., 2009)

Parents also found that when the speech-language therapist either did not understand enough about their child's difficulties or did not listen to parental knowledge on the matter, therapy tended to be unsuccessful.

The SLT failed to understand the impact a brain infection had had, she moved too quickly through each concept she was teaching despite being warned that in the past ideas would be achieved in one session and forgotten in the next. Child was unengaged and refused to participate; SLT didn't change approach, just pushed back and said it was just because it was hard. (SP15).

Parents have a wealth of knowledge about their children and when this is disregarded, parents can feel isolated and frustrated (Franck & Callery, 2004; Marshall & Goldbart, 2008; Ryan & Salisbury, 2012).

For good relationships to be built, parents need to feel that they are being listened to and understood (McNeilly et al., 2017).

When a child has a difficulty with something that the parents are not able to solve on their own, help is difficult to find, and the parents are unsure what the process will look like, this can be a very stressful and perhaps a fearful situation. One way of helping parents through this, is to give them the information they need so that they know what their options are, why their child has this difficulty, and what is going to happen. The end of therapy can also be an unknown and only half of the parents in this study had some idea as to what the end of therapy would look like for them. Some parents also felt as if the end of therapy occurred suddenly and without enough consultation.

> *And, it was an email conversation followed up by a phone call on how he was doing and that prompted the decision by the Ministry to end the speech therapy. I would have thought that they would of seen him. (IP2)*

Once their child had started school, parents found that contact with speech-language therapists could decrease, as the therapists tended to begin to work more with the teachers and the child at school. Communication could happen between the speech-language therapist and the school without the family being aware of what was happening. One parent reported about their experience, which was relatively positive, but they were aware that it was due to the school taking the initiative to keep them in the loop.

> *The school was very good at communicating with us about what was going on, but I could see that for other parents if the school wasn't so good you actually wouldn't really know what was going on all the time. (IP2)*

Barriers around communicating with parents have been reported by speech-language therapists working in school settings, and it is often due to schedules clashing, but it does seem like this could be semi solved by ensuring that parents were included in email conversations and perhaps more general updates could be provided (Mandak & Light, 2018b; Sugden et al., 2017; Tambyraja et al., 2017).

Funding was seen as a barrier for some parents, and this could be a particularly frustrating process as this parent found out.

As soon as she improved, eligibility for therapy was stopped. She would then slip back, and it would be reinstituted. This happened several times over 2 -3 yrs. (SP3)

Parents with children who seemed to have more complex difficulties, as judged from parent reports, appeared to have more difficulties in assessing speech-language therapy that was fitted to their children. Parents spoke of speech-language therapy being discontinued due to speech-language therapists being unable to understand how their children operated and the struggle they had with being diagnosed in order to receive the necessary help. As a result of this lack of understanding both of their child but also their child's difficulties, parents asked for therapists to have more knowledge around these areas.

I would like to see therapists develop better skills in working with behaviour and difference, because often they go hand in hand with speech issues. (SP7)

Information was an area that could present a barrier to the meeting of parental expectations. Parents were expecting to receive information regarding normal development, their child's development, and how their child was progressing. The information that parents received could change their expectations regarding their child's progress however, parents found that they did not necessarily receive the information that they sought.

I was/am expecting information about typical patterns of language / speech development. (SP16)

The need for the provision of information to parents has been something that has been seen throughout the literature (e.g. Hodgetts et al., 2013). In order for parents to be able to build a partnership with their child's speech-language therapist and to make informed decisions, parents need information (Butler et al., 2014). Parents are wanting information, and it has been identified as a core need for parents, however the availability of information can vary (Fordham et al., 2012; McNeilly et al., 2017; Raghavendra et al., 2007; Ryan & Quinlan, 2018). Therefore speech-language therapists have a responsibility to ensure that parents are receiving accurate, timely, unbiased information in a manner that they understand (Shields et al., 2012; Trembath et al., 2016; Ziviani, 2011).

4.5 Clinical implications

There were several important implications for clinical practice that arose from the data collected. These implications included the importance of communicating with parents to ascertain what resources (e.g. time) they had available and tailoring therapy appropriately, the importance of encouraging parents, and providing information to parents.

Parents were aware that home practice and their involvement in their child's therapy was very influential to the amount of progress that their child made. However, it appeared that the amount of time for instance that parents had available was taken for granted. Therefore, more communication with parents to establish what works for them, how home practice tasks are going, and what needs to be approached differently may have a beneficial effect on how parents are able to be involved in their child's therapy. Parents appreciate speech-language therapists taking the time to find out about them and their child and tailoring therapy to them, not the family having to change to fit the therapy.

Parents value therapist encouragement and many parents found that this and having their child's progress pointed out were vital components of the early stages of therapy. Likewise, parents were expecting to receive information regarding speech and language development, and this could very easily tie into parental reassurance as parents will be better able to understand how their child is developing.

Parents also requested that speech-language therapists gain more knowledge around working with children with more complex needs and those who can display challenging behaviours. More knowledge around this area combined with effective communication with parents regarding how best to work with the children will be beneficial. Parents were aware that when speech-language therapists did not have the necessary information regarding their child's difficulties, therapy could be challenging.

4.6 Limitations and directions for future research

A key limitation of this study is the small sample size. Therefore, the findings must be interpreted with caution as it is unlikely that the participants were representative of the general population. Survey information was obtained from 17 respondents and in-depth interview data gathered from four participants. Similarly, the participants were mostly from the Canterbury region which could further

prevent the results being generalised. Parents with children who had received speech-language therapy over a year prior to recruitment were excluded as it was thought that time may begin to affect people's recollection of events. Allowing parents who were excluded by this cut off to participate could allow not only for more participants, but also a wider range of expectations and experiences. The researcher was also relatively inexperienced in interviewing participants, perhaps having a more experienced interviewer may have allowed for more information to be gained from the interviews with parents. Nevertheless, considerable insightful data was gathered.

For the children who either spoke more than one language or had been exposed to another language, more could have been explored around speech-language therapy for the additional languages. While none of the parents in this study, mentioned anything regarding speech-language therapy in the child's additional languages, was this something they either wanted or would want if it were to be offered to them? Considering the increasing amount of bilingual and multilingual speakers in New Zealand, this is something that may require further exploration. No data was collected regarding participant ethnicity, which does prevent the data being used to represent any one ethnic group. Collecting this data in the future, as well as more data regarding the parents' demographics, i.e. age, gender, number of children living at home, etc, may help to highlight areas for improvement or trends in any particular group.

Further research could be conducted to investigate how parents saw themselves being involved in their child's speech-language therapy and how they were involved. This would help highlight how parents felt regarding their level of involvement in their child's speech-language therapy and if they wished it to be different. Similarly, the issue of home practice could also be examined more as to how often parents received it, how often it was completed, what were factors that helped or hindered the completion of it, and how speech-language therapists facilitated the use of home practice activities.

New Zealand parents' use of support groups could be something that could be explored further. What are parents' thoughts around support groups, are they aware of them, and if so, have they been helpful? Is pointing parents towards support groups something that speech-language therapists should be doing more of or, are they already doing this? These questions and more around the use and helpfulness of

support groups for parents with children who are receiving speech-language therapy, could be examined in future research.

4.7 Conclusion

This study set out to examine what New Zealand parents' expectations and perspectives of speech-language therapy services for their children were. Notwithstanding the small sample size and pilot nature of the study, several relevant and informative findings were identified. These include that parents are expecting to be involved in planning and therapy processes for their children's speech-language therapy, parents' expectations of progress, the importance of early intervention and continuity of care for parents and the need for communication between parents and speech-language therapists.

To ensure the ongoing development of therapy services and ensuring effectiveness, communication with parents will be vital to help continue to shape the speech-language therapy field into a place that parents understand, are confident that their children will be given therapy that fits with their life, and their voices are heard and acted upon. It is essential to better understand the expectations, needs, and experiences of parents to allow changes to occur and to create a service that better reflects the overarching principles of Te Tiriti o Waitangi (Treaty of Waitangi). As New Zealand becomes a more multicultural country, incorporating parent perspectives into the provision of speech-language therapy services, will help enrich not only families' lives but also speech-language therapists' lives as well.

Through greater understanding of this information and future information on the topic of parent perspective, it may be possible to improve the lives of children who struggle to develop effective speech, language, and communication skills without the support of speech-language therapists. It may also help improve parents' lives, and as a result of this, families' lives, as their children's struggle to express their thoughts, needs and feelings is lessened.

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Appendices

Appendix A – Ethics approval letter

UC
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Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND·

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2017/55

18 July 2017

Stephanie MacIntyre
Communication Disorders
UNIVERSITY OF CANTERBURY

Dear Stephanie

The Human Ethics Committee advises that your research proposal "Parents' Expectations and Experiences of Speech-Language Therapy in New Zealand" has been considered and approved.
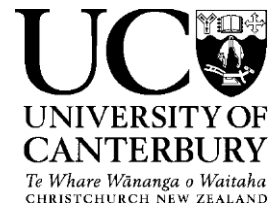
Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 8th July 2017.

Best wishes for your project.

Yours sincerely

R. Robinson

pp.

Associate Professor Jane Maidment
Chair
University of Canterbury Human Ethics Committee

Appendix B – Survey information and consent form

Study Information
Parents' Expectations and Experiences of Speech-Language Therapy in New Zealand (to be provided in electronic form via email or on the first page of online survey)

Tēnā koe,

This email is to invite you to participate in a survey to develop our understanding of what parents expect from, and experiences of speech-language therapy for their children.

I am Stephie MacIntyre, a Master's student at the University of Canterbury and also a Speech and Language Therapist.

The survey consists of closed and open-ended questions. Both quantitative (e.g., demographic information) and qualitative (e.g., respondents' experiences) information is requested. The survey will take approximately 10 minutes to complete.

<<INSERT SURVEY LINK HERE>> (not included in online study information)

Your participation is voluntary and you have the right to withdraw any information you have provided after you have completed the survey. You can also withdraw from the survey if you exit the survey without completing the survey. If you decide to withdraw information, I will delete all your responses to the survey. However, once analysis of raw data starts in July 2017, it will become increasingly difficult to remove the influence of your data on the results.

All information you provide will be treated confidentially. If you do provide identifying information (i.e., to enter the draw for $30 prize vouchers, contact information for sending a summary of results to and/ or willingness to be contacted to participate in face-to-face interview) this will be stored separately from survey responses.

At the end of the survey you will be invited to participate in a brief interview to further explore the issues highlighted in the survey responses. A focus of this interview will be how participants' expectations have been meet or not and experiences of speech-language therapy services.

All information collected during the study will be stored on University of Canterbury computer systems in password protected electronic form and will be destroyed after five years.

The Masters thesis that this data will contribute to will be a public document and will be available through the UC Library. The results of the project may also be published. However no personally identifiable information will be reported.

Please indicate your consent to participate by referring to the consent information provided on the survey.

The project is being carried out as a requirement of the completion of the Master of Science in Speech and Language Sciences by Stephie MacIntyre (Stephie.macintyre@pg.canterbury.ac.nz) under the supervision of Dr. Dean Sutherland (dean.sutherland@canterbury.ac.nz). We can be contacted to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants can address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

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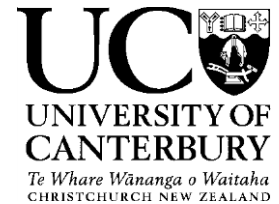
Parents' Expectations and Experiences of Speech-Language Therapy in New Zealand
(to be provided in electronic form at the start of the survey form)

☐ I have read the study information and agree to participate.

☐ I understand that participation is voluntary and I may withdraw without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable (before 31st August 2017).

☐ I understand that any information or opinions I provide will be kept confidential to the researcher and her supervisor, Dr. Dean Sutherland, and that any published or reported results will not identify me or the Speech-language therapists I know. I understand that a thesis is a public document and will be available through the UC Library.

☐ I understand that I can contact the researcher Stephie MacIntyre (stephie.macintyre@pg.canterbury.ac.nz) or Dr. Dean Sutherland (dean.sutherland@canterbury.ac.nz) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz)

☐ I would like a summary of the results of the project (please complete contact details section)

☐ I wish to enter the draw for the $30 fuel vouchers (please complete the contact details section)

☐ I am available to be contacted to participate in a follow-up interview (please complete contact details section)

Name: _____

Email address: _____
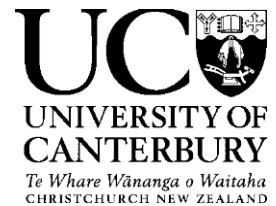
Appendix C – Information and consent form for interviews

Study Information
Parents' Expectations and Experiences of Speech-Language Therapy in New Zealand
For Interview component

Tēnā koe,

I am Stephie MacIntyre, and am currently a Master's student at the University of Canterbury and also a Speech and Language Therapist.

Thank you for recently completing the online survey about parents' expectations and experiences of speech-language therapy in New Zealand and for indicating your willingness to participate in a follow-up interview. A focus of this interview will be how participants' expectations of speech-language therapy were met or not.

Some questions that you might be asked could be:

- Tell me about your expectations for your child's therapy.

- Was there anything that you or the therapist did to help meet your expectations?

- Were there any barriers to your expectations being met?

The interview will take between 15-60 minutes. The interview will take place either at the University of Canterbury or another venue that would better suit you. The interview will be audio recorded, then transcribed and you will be given the opportunity to review your responses and, if you wish to do so, edit and / or delete responses before these are analysed.

Participation in this interview is voluntary and you have the right to withdraw the information you have provided. If you decide to withdraw information, I will delete all your responses. However, once analysis of raw data starts on 31st October 2017, it will become increasingly difficult to remove the influence of your data on the results.

All data collected during the study will be stored on University of Canterbury computer systems in password protected electronic form or in physically in locked storage cabinets and office space and will be destroyed after five years.

The results of the project may be published, but you may be assured of the complete confidentiality of data provided by you. To ensure anonymity and confidentiality, only my supervisor and myself will have access to completed surveys and participant information. If you do provide identifying information (i.e., desire for summary of results and/ or willingness to be contacted to participate in face-to-face interview) this will be

stored separately from the responses you make to the survey. The Masters thesis that this data will contribute to will be a public document and will be available through the UC Library.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Please indicate on the consent form if you would like to receive a copy of the summary of results of the project.

The project is being carried out as a requirement of the completion of the Master of Science in Speech and Language Sciences by Stephie MacIntyre under the supervision of Dr. Dean Sutherland (dean.sutherland@canterbury.ac.nz). He can be contacted to discuss any concerns you may have about participation in the project.

If you agree to participate in this study please complete the following consent information.

Parents' Expectations and Experiences of Speech-Language Therapy in New Zealand

Consent Information for participants in this study

☐ I have read the study information and agree to participate in this interview.

☐ I understand that participation is voluntary and I may withdraw without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable (before 31st October).

☐ I understand that the interview will be audio recorded and that I will be able to review my responses and edit/delete my responses before they are analysed.

☐ I understand that information or opinions I provide will be kept confidential to the researcher and her supervisor, Dr. Dean Sutherland and that any published or reported results will not identify the participants or their private clinic. I understand that a thesis is a public document and will be available through the UC Library.

☐ I understand that I can contact the researcher, Stephie MacIntyre (stephie.macintyre@pg.canterbury.ac.nz), or Dr. Dean Sutherland (dean.sutherland@canterbury.ac.nz) for further information.

☐ I would like a summary of the results of the project (please complete contact details below)

Name: _____

Email address: _____

Please sign below

Signature:_____   Date:_____

Appendix D – Survey questions

Survey of Parents' Expectations and Experiences of Speech-Language Therapy in New Zealand

(for entry into Qualtrics system)

- Consent information
    1. Consent statements (from consent sheet) (check boxes)
    2. Do you want a summary of the results of the project? (check box)
- Demographic and therapy information
    3. Age at beginning speech-language therapy (free entry)
    4. Gender (free entry)
    5. Area of New Zealand you live in (chose from options)
    6. First language (free entry)
    7. Does your child speak any other languages fluently (i.e. is able to hold a conversation in them)? (yes/no)
    8. Other languages spoken fluently (free entry)
    9. What was your reason for seeing speech-language therapy services? (free entry)
    10. How long did therapy last for? (free entry)
    11. What services did you receive? (chose any from private practice, Ministry of Education, District Health Board, Early intervention centre or University clinic)
- Expectations information (all questions are to be answered on a 7-point scale plus a further not applicable option, unless otherwise marked)
    12. I expected to be involved in my child's speech-language therapy
    13. I expected to be involved with the planning of my child's speech-language therapy
    14. I expected to be given home practice/homework to do with my child
    15. I expected to learn strategies to help my child
- Experiences information (all questions are to be answered on a 7-point scale plus a further not applicable option, unless otherwise marked)
    16. I was involved in the planning of my child's speech-language therapy (yes/no/maybe)
    17. I was given home practice/homework to do with my child (yes/no/sometimes)
    18. I understood the home practice/homework (if answered yes to previous question)
    19. Were your original expectations for your child's speech-language therapy met?
    20. How did your expectations for your child's speech-language therapy change? (free entry)
    21. I felt like the therapist understood what I wanted my child to achieve through speech-language therapy
    22. I understood the focus of my child's speech-language therapy
    23. I felt that the therapist was able to adjust the speech-language therapy to fit my child and family
    24. I understood what was going to happen at the end of my child's speech-language therapy
    25. The things that I most wanted to happen as a result of the speech-language therapy were (free answer)
- Additional information
    26. Any other information or thoughts you would like to share (free answer)

- Prize, interview, and summery contact information
    27 Are you available for a follow-up interview? (yes/no, if Canterbury was selected in the area of NZ they lived in)
    28 Do you wish to enter the draw to win one of 10 $30 petrol vouchers? (yes/no)
    29 Thank you for wishing to participate in a follow-up interview. Please enter your name and email address below to allow me to get in contact with you. (Name and Email address – if answer yes to follow-up interview)
    30 Thank you for completing this survey. Please enter your name and email address to enter the draw to win one of 10 $30 petrol vouchers. (Name and Email address – if yes to prize draw)
    31 Thank you for completing this survey. Please enter your name and email address to be sent a summary of the results of this project. (Name and Email address – if yes to summary)

Appendix E – Interview Questions

1. Tell me about your expectations for your child's therapy? (including what they wanted their child to be able to do as a result of the therapy)

2. What were you expecting the therapy to look like/how did you think the therapy would go?

3. How would have you liked the therapy to have gone?

4. Was there anything that happened that you weren't expecting during therapy?

5. Was there anything that you or the therapist did to help meet your expectations?

6. Were there any barriers to your expectations being met?

7. If you could have changed something about your child's therapy what would it have been?

8. What did you find was the most helpful aspect of the therapy?

9. In an ideal world, how would you see funding for speech-language therapy working?

10. If there was one thing you could tell all the speech-language therapists out there, what would it be?