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**KiwiChat Camp: Experiences and Perceptions of Children
with Complex Communication Needs and their
Family/Whānau**

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Abstract

Children with complex communication needs (CCN) who use augmentative and alternative communication (AAC) require a significant amount of intervention to achieve communicative competence. This study explored the perceptions and experiences of 16 children with CCN and their families who attended KiwiChat Camp, an intensive 5-day camp focused on using AAC in everyday contexts. Very few studies have explored the perceptions and experiences of camp interventions. KiwiChat camp involved explicit training sessions for parents and small group intervention for children who use AAC. All of the family members (parents, siblings and children who use AAC) were immersed in aided language stimulation throughout the day. They interacted with other families of children who use AAC and older AAC mentors. Pre-and-post data were collected through camp surveys for parents and children who use AAC and semi-structured interviews with parents and siblings. The quantitative data were analysed using descriptive statistics, while the qualitative data were analysed using a general inductive approach. The results indicated that families enjoyed the camp experience and parents experienced increased motivation, inspiration and empowerment following camp. However some felt overwhelmed during camp. They also perceived an increase in a range of communication outcomes (increased AAC use, confidence and knowledge) and sociocultural outcomes (connections with others who use AAC, a sense of belonging and development of identity). Recommendations for future camps and research studies are outlined.

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Chapter One: Introduction

The ability to communicate is arguably one of the most important aspects of human life. It is a foundation for learning and is a basic human right (United Nations, 1948). In New Zealand, communication is both a democratic and a civil right that is protected by legislation (New Zealand Bill of Rights Act, 1990). Communication is the act of giving and receiving information and requires communication partners to have a shared and agreed upon 'language' (Anderson & Shames, 2006). Being able to communicate effectively allows a person to engage in a range of important communicative acts such as forming relationships; expressing thoughts, feelings, opinions and personality; asking questions; finding out information; as well as sharing personal, technical or humorous information (Beukelman & Mirenda, 2013; Light & McNaughton, 2014). People can communicate through different modalities, for example, speech, body language, gestures, sign language, eye gaze, intonation, facial expression and writing (Beukelman & Mirenda, 2013).

For individuals with complex communication needs (CCN), being able to communicate competently and autonomously means that they can engage in these important communicative acts. CCN is defined as a significant speech, language, cognitive and/or motor impairment whereby an individual is not able to communicate effectively with speech alone (Iacono, 2014; Justice, 2009). CCN may be the result of a developmental disability, such as autism spectrum disorder or cerebral palsy, or an acquired disability, such as a traumatic brain injury or stroke (ASHA, 2017a). People with CCN are a diverse

group and come from all age groups, genders, cultures and socioeconomic backgrounds (Iacono, 2014). They often have concurrent visual, auditory, physical, sensory, and/or cognitive impairments (Beukelman & Mirenda, 2013), which contribute additional challenges for them to overcome or circumvent. These factors impede their ability to meet all of their daily communication needs using speech alone and often result in the need to use augmentative and alternative communication (AAC) (Beukelman & Mirenda, 2013).

AAC encompasses a range of systems and strategies which allow individuals with CCN to express their needs, wants, feelings and ideas (Beukelman & Mirenda, 2013). Being able to use a conventional AAC method is important, as a shared and agreed upon method of conveying information is required for communicative interactions to be successful (Light & McNaughton, 2014).

AAC is a general term which involves any technique or system which supplements speech or writing to support receptive language and the expression of thoughts, needs, wants and ideas (Murray & Goldbart, 2009). AAC can be used with individuals of any age and with any level of cognitive or physical ability (Beukelman & Mirenda, 2013). AAC is augmentative when it supplements existing speech and is alternative when it is used in place of speech (ASHA, 2017a).

AAC can be described as a continuum ranging from no-tech to low-tech to high-tech (Beukelman & Mirenda, 2013). No-tech systems, such as gesture, pointing or sign

language does not require the use of any other objects or technology. Paper-based systems are included in the low-tech category and encompass picture communication boards or books. High tech systems are electronic devices such as tablets and can be used with a range of access methods, such as direct access, switching, head mouse, joystick or eye gaze (Beukelman & Mirenda, 2013). It is important to note that AAC systems exist along a continuum rather than a hierarchy, as no one AAC system is better than another and different systems can be used together (Iacono, 2014).

AAC is often a multimodal process. For example, individuals may use a combination of speech, although it may be difficult to understand; gestures; signs or behaviours which may not be 'typical' due to motor impairments; and their low or high tech communication systems (ASHA, 2017b). The mode that they choose to use may depend on the familiarity of the communication partner, the context they are in, and also the complexity of the information they need to share (ASHA, 2017a).

It is well established that individuals who use AAC require a significant amount of intervention to develop autonomous communication skills (Beukelman & Mirenda, 2013). There are many different approaches to providing this intervention, with some being more or less successful in supporting individuals with CCN to learn, maintain, and generalise their communication skills (Beukelman & Mirenda, 2013).

Historically, AAC intervention was completed in one to one sessions with a speech-language therapist (SLT). Yet, in more recent years, there has been increased

recognition of the need for AAC intervention to be carried out in more naturalistic and functional contexts, such as in the home or classroom, or in the community (Light & McNaughton, 2014). This is because people learn best in natural environments where they can practice functional communication skills in the real world (Angelo, Kokoska, & Jones, 1996). By providing intervention in natural contexts, communication gains are more likely to generalise and be maintained. Parents and siblings, teachers and peers can take part in supporting this intervention and therefore provide continuation and reinforcement of the intervention goals throughout the day.

AAC Camps

AAC camps were first introduced in the 1990s to support individuals who use AAC and their families to increase their communicative competence by providing brief but intensive AAC intervention (Bruno & Dribbon, 1998). The general aims of these camps are to provide an environment for individuals who use AAC to connect with others who use AAC and their families; to be immersed in evidence-based intervention techniques; and to practice communication skills with new people. Camps are run around the world (Prentke Romich Company, n.d.). However, there is very little information about the experiences, perceived benefits, and challenges of providing intervention in this intensive 'camp' style. There is limited research about how effective camps are in increasing the confidence, knowledge and skills of individuals who use AAC as well as their parents, siblings and extended family. There are some informal articles on social media (Craig, 2017) which indicate that parents value camp

based AAC intervention. However, there are few research studies which investigate their experiences and perceptions in detail.

Rationale for this Study

TalkLink Trust is a New Zealand based charitable trust, which employs SLTs, occupational therapists and specialist teachers (TalkLink Trust, 2018b). TalkLink staff complete AAC assessments, submit funding applications and provide training for families and professionals who work with individuals of all ages who require the use of AAC systems (TalkLink Trust, 2018b). TalkLink provides a free service across all regions of New Zealand.

TalkLink run KiwiChat Camp biannually in New Zealand (TalkLink Trust, 2018a).

KiwiChat Camp is a camp for children and families who use AAC to connect, practice social communication skills, develop life skills, meet positive role models who use AAC and have fun (TalkLink Trust, 2018a). The children's parents participate in training focused on learning strategies to support their children to use AAC and to develop language and social communication skills. KiwiChat Camp also gives families a chance to enjoy a typical family camp experience. Children and families are financially supported to attend by the New Zealand Ministry of Health and the Accident Compensation Corporation (ACC); charities such as Wilson Home Trust, Lions and Rotary; as well as through fundraising initiatives such as the KiwiChat Camp GiveALittle page, movie nights, school mufti days and other individual donations.

TalkLink collects feedback forms after each camp. However, formal research about the experiences and perceptions of the children and families who attend camp has not been previously completed. TalkLink have developed their own camp timetable, training programmes and style of 'doing things' for KiwiChat Camp based on previous years of experience and email contact with camp organisers in other countries, as there is very little research or recommendations to guide the camp intervention programme.

I have worked for TalkLink as an SLT for five years and have been on the planning committee for, and a leader at, KiwiChat Camp twice at the time of this study. My previous observations of the experiences of families at KiwiChat Camp and knowledge of the limited research around camps, propelled me to complete this study. The information about KiwiChat Camp and TalkLink Trust above, comes from my clinical experience working at TalkLink and led to the formulation of my research question.

This project aimed to explore the experiences and perceptions of the children and families who attended KiwiChat Camp in 2016. It is hoped that the information gained from this project will fill some of the research 'gaps' and provide TalkLink and other AAC camp organisers with recommendations about how to improve future camps based on the experiences and perceptions of camp for children and families. Both quantitative and qualitative methods were used to gain a rich understanding of the camp experience.

The Research Aims

This research explored the following question:

What are the experiences and perceptions of families (parents, siblings and children who use AAC) who attended KiwiChat Camp?

The Structure of this Thesis

Chapter One has provided an overview of the research carried out for this thesis, including the purpose, rationale and definitions of key concepts. Chapter Two provides a synopsis of literature relevant to the intervention strategies carried out at camp and then reviews existing research related to AAC camps. Chapter Three describes the methodology for this study including the data collection and analysis approaches employed. It also outlines the ethical considerations and positionality. The results and key findings are presented in Chapter Four. The findings are then discussed in Chapter Five and related back to best practice and the literature. Finally, Chapter Six explores the limitations of the study, how the key findings relate to the research question and the clinical implications for SLTs working with children who use AAC. Considerations for future research are also outlined.

Chapter Two: Literature Review

This chapter reviews the existing body of literature related to AAC camps. However, before this, the language development process for children who use AAC is discussed and aided language stimulation is defined and reviewed. Then family-centred practice, family support needs and the effects of group therapy are addressed. Each of these aspects influence the content, delivery and rationale underpinning AAC camps.

Language Development in AAC

Learning language when using an AAC system differs from typical language acquisition through speech (Beukelman & Mirenda, 2013). Many challenges and barriers affect the development of communicative competence when using AAC.

Communicative competence. Light's (1989) Model of Communicative Competence outlines four main components which are required for an individual who uses AAC to develop communicative competence: linguistic, operational, strategic and social competence (Light, 1989). Linguistic competence refers to the receptive and expressive language skills of the individual with CCN, as well as their knowledge of the 'language' codes of their AAC system (e.g., the content, form and use of the system). Operational competence encompasses the technical skills required to operate the AAC system accurately and efficiently. Strategic competence involves the development of compensatory strategies, which help individuals who use AAC to communicate efficiently within the restrictions of their AAC system. Strategic competence includes

repairing communication breakdowns, compensating for a slower rate, communicating with unfamiliar communication partners and expressing words or concepts that are not available on their AAC system. Social competence comprises the sociolinguistic and sociorelational skills of the individual who uses AAC. Sociolinguistic skills include initiating, maintaining, developing and terminating a communicative interaction. In other words, these are the knowledge, judgement and skills “that govern when to speak, when not to speak, what to talk about and with whom, when, where and in what manner” (Beukelman & Mirenda, 2013, p. 12). Sociorelational characteristics include portraying a positive self-image, taking an interest in others, being active in conversations and putting communication partners at ease (Beukelman & Mirenda, 2013). More recently, Light and McNaughton (2003; 2014) expanded this model to discuss the impact of psychosocial factors, such as motivation, attitudes, resilience and confidence, and environmental supports and barriers, on communicative competence.

Challenges. Children who use AAC face a number of challenges when learning language. They are unable to use new words unless someone adds them to their AAC system or they can spell the word (Beukelman & Mirenda, 2013). They tend to use 1-2 symbol utterances during most communication interactions (Clendon & Anderson, 2016; von Tetzchner & Stadsleiv, 2016). This could be due to having a limited vocabulary available to them on their AAC system, or not yet having the grammatical skills to construct a sentence. It could also be because they are trying to communicate more efficiently, as constructing messages on an AAC system is much slower than speech (Beukelman & Mirenda, 2013). Children who use AAC often have delayed

syntactic and morphological development, meaning that creating sentences that make sense and that cue the listener with the correct verb tense can be difficult (Clendon & Anderson, 2016). Children who use AAC may also become passive communicators because the adults around them are excellent at anticipating their needs (Anderson, Balandin, & Stancliffe, 2016; Angelo, 2000).

Many of these difficulties may be due to intrinsic difficulties, such as cognitive impairment, sensory processing issues, physical difficulties or communication delays or disorders. However, the challenges may also be due to factors related to the AAC system or opportunity barriers. The interaction between these issues is complex (Clendon & Anderson, 2016; Light, 1997).

AAC factors. Until individuals who use AAC develop conventional spelling skills and can use a text-to-speech based system, they are dependent on others to provide the vocabulary on their AAC systems. Unfortunately, individuals often have limited vocabulary and language functions programmed into their systems (von Tetzchner & Stadskleiv, 2016). Individuals may also have difficulty learning to talk about anything other than the 'here and now' if their system lacks the morphological markers and syntactical links or vocabulary that allow them to talk about the past or future. Conversely, if the system is programmed to predict and automatically correct grammatical structures, then the individual may not learn how to manipulate and use these morphological markers and syntactical links (Clendon & Anderson, 2016).

Individuals who use AAC are often only provided with choice making opportunities rather than with access to a rich variety of vocabulary options and language functions (von Tetzchner & Stadskleiv, 2016). Although choice making is an important language function, teams must remember that commenting, sharing information, asking questions and sharing feelings are among some of the other language functions that an individual with CCN must have access to (Beukelman & Mirenda, 2013).

Environmental barriers. The most significant environmental barrier for individuals who use AAC is a mismatch, which occurs frequently, between the language modality that they use for language output and the modality used around them for language input (Clendon & Anderson, 2016). Communication partners may use verbal language only, but expect the individuals who use AAC to respond and express themselves using their AAC system. These two modalities differ regarding form (auditory versus visual) and linguistic rules (Light, 1997). Individuals who use AAC need to learn the link between spoken language and its symbolic representation on their AAC system and often communication partners do not provide the explicit links or 'translation' between the two (Blockberger & Johnston, 2003).

Individuals must have access to an AAC system in all environments and with all communication partners to learn language (Beukelman & Mirenda, 2013). This includes times when it is difficult to use AAC, such as the pool, bathroom and hospital room. Often due to logistical, technological or positioning issues, having access to a

comprehensive AAC system is restricted and this is a significant barrier to successful language learning (von Tetzchner & Stadskeiv, 2016).

Individuals who use AAC are often not given enough time to construct a message due to their slow rate of message creation. Therefore they have reduced opportunities to practice language generation (Clendon & Anderson, 2016; von Tetzchner & Stadskeiv, 2016). Using an AAC system is always going to be slower than speech. Often individuals who use AAC are not finished generating a message before the conversation has moved on to a new topic and therefore the communication opportunity is lost (Murray & Goldbart, 2009).

Team members may lack the skills required to become competent communication partners (von Tetzchner & Stadskeiv, 2016). Lack of access to SLTs with experience in AAC, rural locations and other barriers may affect how much training teams receive. As aided language learning is different from typical language learning, adults and peers need to be taught how to support, model and scaffold aided language.

Communication partners may lack motivation or feel too overwhelmed to put effort into modelling an AAC system when they have other care or medical needs to manage (Bridges-Bond, 2011; Light, 1997). Teams often also feel isolated if the individual they support is the only person they know who uses an AAC system (von Tetzchner & Stadskeiv, 2016). Isolation may lead to feelings of inadequacy in teaching language and providing communication opportunities throughout the day. It may also result in

guilt and doubting their parenting or teaching abilities if they are not able to connect with others and discuss challenges and successes (Bridges-Bond, 2011).

Individuals who use AAC may never or seldom meet older and/or competent individuals who use AAC (von Tetzchner & Stadskleiv, 2016). This isolation can lead to feelings of loneliness (Ballin & Balandin, 2007; Cooper, Balandin, & Trembath, 2009a). They also often lack the opportunity to see what they could achieve with their AAC system if they learnt to use it more proficiently (e.g., graduate from school or university and get a job, or have relationships of equally balanced power with people in their social circles) (Beukelman & Mirenda, 2013).

Cultural considerations. The 'cultural language learning context' refers to the family's, community's and society's values, priorities and expectations for learning language (Hetzroni & Harris, 1996). This communication culture includes all of the shared rules of a community, which specify appropriate behaviours (Bridges, 2004; Hetzroni & Harris, 1996). Priorities and expectations may change over time based on medical, educational and other needs but parents of preschoolers in one study ranked communication as the most important achievement for their children (Light, 1997). Priorities will influence how much time and effort is spent on implementing AAC and learning language (Light, 1997).

Individuals with CCN may be alienated from their community if they are seen to be breaking cultural rules (Hetzroni & Harris, 1996). Alienation happens when culturally

sensitive communication is not focused on as part of learning the AAC system (Hetzroni & Harris, 1996). This requires the SLT and team members to immerse themselves in the family and school environments. Emersion allows the team to fully understand the cultural and religious values and practices, language structure, vocabulary and social rules of the family before starting training or intervention (Bridges-Bond, 2011). In New Zealand, SLTs are expected to acknowledge and integrate the principals of The Treaty of Waitangi (participation, protection and partnership) when working with families (Ministry for Culture and Heritage, 2018). Cultural sensitivity can be achieved through being aware of their own cultural values, beliefs and behaviours as well as those of the families they support (American Speech-Language-Hearing Association, 2008; Ministry of Health, 2016).

The language background of the home and educational environments may differ. This may be confusing for the individual who uses AAC as they may struggle to determine which communication rules to apply in each context. They need to learn how and when to switch between languages but often only have access to one language (usually the school language) on their AAC system (Light, 1997). Their system may also not 'match' them as the team may be unable to programme dialect and vocabulary differences into the device (Bridges-Bond, 2011). The mismatch may mean that the individual who uses AAC cannot use culturally appropriate slang (Bridges, 2004). They may also not have access to a voice from their region, culture or dialect as there are only a limited number of voices and symbol sets available on most high tech AAC systems and these often do not match minority groups (Bridges, 2004). Soto's

perspective from several years ago was that cultural awareness amongst the AAC community had come a long way, however further work was needed to increase cultural responsiveness (Soto, 2000). There is limited evidence of recent research in this area. Additionally, no sources were found relating to Māori culture and AAC. The New Zealand Disability Strategy includes cultural considerations for individuals with a disability but is not specific to those with CCN or who use AAC (Office of Disability Issues, 2016).

Identity. Another aspect of language learning and culture is identity. Identity is defined as:

A set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person“ (Burke & Stets, 2009, p. 3).

Identity has two types: personal identity and social identity. Personal identity is established and modified through relationships with family and peer relationships. It is the story you tell others. Social identity is the story that others tell about you and is the way that you see who you are based on which groups you belong to (Burke & Stets, 2009). Allan, Frawley and Balandin (2016) completed a literature review of individuals who use AAC and how they understand their identity. They observed a lack of research in this area and concluded that there is very little understanding about the development of identity of individuals who use AAC. There is some research on the perceptions, challenges and frustrations of having CCN but at this stage, it is unknown

what issues influence identity. For example, what meanings and characteristics individuals with CCN hold; what roles they want to play in society; and how their identity is affected by family, friends, community and schools (Allan et al., 2016).

Your identity as a child or teenager is not the identity you grow up to have as an adult as there are many factors which grow, change and shape this over time (Allan et al., 2016; Grassmann, 2002; Smith, 2005). Identity is built through interactions and showing others who you are through what you think and your understanding of the world (Grassmann, 2002; Howery, 2016). One study of teenagers who use AAC proposed that for these individuals, the risk of mental health disorders and loneliness may be reduced if identity is developed through establishing secure social networks with other individuals who use AAC (Smith, 2005). A more recent in-depth ethnographic study of teenagers who use AAC, found that there was a difference between the how the teenagers identified themselves and the identity that others perceived of them (Wickenden, 2011). Using AAC offers an opportunity for individuals with CCN to define their identity and to display their unique personality, interests, cultural perceptions and way of experiencing the world that would otherwise be unseen (Grassmann, 2002; Howery, 2016). It allows them to be seen and heard (Howery, 2016).

Aided Language Stimulation

As discussed, the quality and quantity of language input is key to acquiring language. However, children with CCN typically receive language input in spoken form, which

does not match their expressive language output through AAC (Smith & Grove, 2003). To increase the balance between modalities, aided language stimulation (ALS) is required.

Definition. ALS is a strategy of increasing language input through modelling AAC in everyday contexts. It involves the communication partner talking to the individual who uses AAC, while simultaneously selecting keywords on the AAC system in naturalistic and motivating contexts (Beukelman & Mirenda, 2013; Sennott, Light, & McNaughton, 2016). ALS provides a model of language content (semantics), form (syntax and morphology) and use (pragmatics) which teaches the individual symbol meanings and how to use symbols functionally in real-life contexts (Allen, Schlosser, Brock, & Shane, 2017). Comprehension is increased as a) the child is not pressured to use the AAC system but can watch and learn to use it and b) because visual information is combined with auditory information (Beukelman & Mirenda, 2013). ALS is also called 'modelling' as the communication partner models effective ways to use the AAC system to communicate (Allen et al., 2017).

Summary of studies. Two meta-analyses examining the effectiveness of ALS were recently published. Allen et al. (2017) attempted to address some limitations inherent in Sennott, Light and McNaughton's (2016) review. Both reviews indicated that ALS is an effective and efficient method of increasing the communication skills of children with CCN, with a range of diagnoses, who use AAC. Specifically these reviews demonstrated that ALS led to increases in a) semantics, particularly an increase in

receptive and expressive vocabulary, b) pragmatics, predominantly an increase in turn taking, c) syntax, marked by an increase in combining symbols to create longer phrases and finally d) morphology, evidenced by individuals starting to use morphological forms. The results also suggested that ALS is an efficient intervention method as most of the studies required 15-30 minutes a few times per week to demonstrate increases across language domains.

A range of communication partners provided ALS in the studies reviewed, for example, SLTs, parents, and teacher aides (Allen et al., 2017; Sennott et al., 2016). Allan et al. (2017) stated that investing time in training communication partners to carry out this type of intervention is advisable, as they are with the child throughout the day. Only two of the studies reviewed investigated the effect of teaching communication partners ALS strategies in groups. However, in both of these studies, this was shown to be effective (Ferm, Andersson, Broberg, Liljegren, & Thunberg, 2011; Jonsson, Kristoffersson, Ferm, & Thunberg, 2011).

The authors of the meta-analyses noted that studies researching the effect of ALS, need to be of a higher quality. A number of studies provided inadequate information about the participants, the intervention (dosage, density and input formats), and the methods. The lack of information reduced the validity. Future studies need to include larger sample sizes or replicate studies with different children as currently the research has only been carried out on a few hundred children (Allen et al., 2017; Sennott et al., 2016).

Family Centered Practice

Families or whānau are well recognised as one of the most important aspects of SLT service delivery from assessment through to intervention and monitoring (Shire & Jones, 2015). An individual with CCN often has a few key communication partners who provide lifelong support and these people are often their parents and siblings and sometimes extended family/whānau. They are generally the people who spend the most time with the person who uses AAC and therefore engage in the most communicative interactions with them (Angelo et al., 1996). It is, therefore, essential that SLTs work collaboratively with family/whānau to provide training, support and empowerment (Bailey, Parette, Stoner, Angell, & Carroll, 2006; McNaughton et al., 2008). Sadly, one literature review of 40 single subject design AAC intervention research studies between 1997 and 2003 found that parents, teachers, siblings and peers were often not involved in intervention (Snell, 2006). Families need to have input into vocabulary selection, types of AAC systems selected, goals, and intervention (Anderson, Balandin, & Stancliffe, 2014; Beukelman & Mirenda, 2013; McNaughton & Rackenspeger, 2008).

Family members/whānau know the individual who uses AAC best and are able to identify challenges and needs as well as encourage strengths and interests (Anderson et al., 2014). When families are not included, empowered, and valued during AAC assessment and intervention, AAC use in the home and community is often minimal to none (Anderson et al., 2014; Angelo et al., 1996). Being unsupported to use an AAC

system is ranked as one of the top 15 reasons for abandoning use (Johnson, Inglebret, Jones, & Ray, 2006). The combination of whānau and SLT knowledge and support increases the chances of carryover and functional use of the AAC system in everyday life (Anderson et al., 2014; Angelo, 2000; Bailey et al., 2006).

Family support needs. Despite recognition of the importance of training and support for families, there is very little research to guide the form and content of this training (Anderson et al., 2016). Two systematic reviews (Kent-Walsh, Murza, Malani, & Binger, 2015; Shire & Jones, 2015) explored the efficacy of teaching communication partners to engage with children who use AAC. The authors reviewed many different methods of providing training and almost all demonstrated moderate to large effect sizes immediately following a range of intervention methods and during the maintenance period for children with a range of diagnoses and using a range of AAC systems. In addition, most of the studies found that children's receptive and expressive language skills increased, as well as their speech and/or vocalisation rates (Kent-Walsh et al., 2015; Shire & Jones, 2015).

Families across several studies have emphasised the importance of having frequent and open communication with the whole AAC team (Angelo, 2000). Families experience increased demands on their time related to AAC use and increased stress; they can become overwhelmed if responsibilities are not shared and supported (Anderson et al., 2016; Angelo, 2000; McNaughton et al., 2008). Discussions about how best to support children who use AAC should not stop once they have an AAC system

in place, but need to be ongoing to meet the ever-changing needs of the child, their family and other communication partners (Anderson et al., 2016). AAC abandonment often occurs because a communication system worked well at the time that it was funded but families do not know how to continue using it in different circumstances (Anderson et al., 2016; Angelo, 2000). This means that SLTs need to develop strong positive relationships with families. Service providers need to offer ongoing reviews and support from SLTs, so that families feel that they can ask for more support when required.

Technical skills. Families need to be provided with technical training about adding vocabulary, programming the device and locating vocabulary before they are taught how to use the communication system within social interactions (Bailey et al., 2006; McNaughton et al., 2008; Shire & Jones, 2015). Many families have reported that they do not receive enough training and support and feel isolated (Anderson et al., 2014; Bailey et al., 2006) and therefore go online to access sometimes questionable information and connect with others (Anderson et al., 2014, 2016). SLTs need to provide families with web links to online resources, blogs, training videos and other educational materials to ensure that families access high-quality information (Anderson et al., 2016).

Language learning. After families grasp the basic technical aspects of the AAC system, they need to learn to use ALS, create communication opportunities for their children and scaffold interactions (Light & Drager, 2007; Scope Australia, 2018).

Parents and close family members often know their child's non-verbal communication, facial expressions, gestures and routines so well that they anticipate most of their needs. Children can often grow up into passive adults if they never need to request, express their feelings or ask questions, as everything is done for them before they even realise they need or want it (Anderson et al., 2016; Angelo, 2000). Responding to communication attempts (even when they appear random), sabotaging routines, prompting spontaneous initiation and using a range of language functions (such as requesting, commenting, greeting, answering questions, asking questions, sharing personal information) are all strategies which increase the communicative competence of children who use AAC (Anderson et al., 2016; Scope Australia, 2018; Shire & Jones, 2015). These strategies require explicit training from an SLT as they often do not come instinctually to parents and other communication partners (Shire & Jones, 2015).

General training recommendations. Families benefit from training across multiple activities (Shire & Jones, 2015). Many of the studies included in Shire and Jones' (2015) systematic review found that parents who were only trained in how to provide AAC support to their children in one activity, for example, book reading, showed very little generalisation of these skills to other contexts, such as pretend kitchen play. Lack of generalisation shows that communication partners need to be shown a range of strategies across a range of activities, including but not limited to reading, meal times, bath times, indoor and outdoor play, transitions and learning activities.

Families also need to learn how to implement AAC across multiple environments (Anderson et al., 2016; Shire & Jones, 2015). It is often not feasible for an SLT to travel to all of the environments that the family frequent, however, it is advisable to discuss ideas and barriers for AAC use across environments (Angelo et al., 1996). For instance, parents may want to problem solve access to a communication system at the swimming pool or at horse riding, where the communication environment is different from normal.

Families need to be able to continue to implement the strategies and ideas they have learnt over time when SLT support is withdrawn (McNaughton et al., 2008; Shire & Jones, 2015). This means that SLTs need to check understanding, observe adults trying the techniques and provide feedback on how to improve their techniques (Angelo et al., 1996). The coaching role of the SLT is important as it ensures that the family members can try strategies and seek clarity with the SLT present (Anderson et al., 2014).

Motivation and empowerment. In addition to gaining technical skills and understanding language development, parents require motivation and empowerment to implement AAC on a daily basis. Motivation was included in the updated version of the Model of Communicative Competence, as it is understood to be an important aspect of family-centred practice (Light & McNaughton, 2014). Motivation is a dynamic driving force which activates movement towards a chosen outcome (Poulsen, Ziviani, & Cuskelly, 2015). It requires direct and purposeful attention and commitment,

persistence, and the use of effective knowledge and strategies to achieve goals (Poulsen et al., 2015). According to self-determination theory by Ryan and Deci (2000), motivation has three basic psychological needs: autonomy (having choices and making decisions), relatedness (feeling connected and having a sense of belonging) and competence (having knowledge and skills to experience mastery).

Fishman and Nickerson (2015) investigated the extent to which motivational factors represented in the Model of Parent Involvement (Hoover-Dempsey & Sandler, 1995; Hoover-Dempsey, Walker, & Sandler, 2005) affected parents' involvement in AAC at home, school and within the special education system. This model does not include all of the factors that may affect motivation but is a framework, which may be useful for exploring this issue. The results show that parental motivation is complex and multifaceted. The following factors were found to increase parental motivation: increased knowledge and skills, the perception of having time and energy, parental empowerment, specific invitations from school teams to be involved with AAC implementation, and higher levels of parental education. A significant outcome of this study was that parental motivation increased when children specifically requested that their parents be more involved in their AAC journey. Another researcher found that motivation to implement AAC, as well as empowerment, increases through exposure to diverse viewpoints and connecting with other families who are on the same journey and face similar challenges (Kingsnorth, Gall, Beayni, & Rigby, 2011).

Empowerment is a social process of taking control of your own life and acting on issues you define as important (Zimmerman, 1995, 1998). Parental empowerment is developed by building on existing parental strengths to develop new strengths (Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010). Empowerment allows parents to make decisions for their child, have independence and feel that they have control as they deal with challenges related to raising their child with CCN (Resch et al., 2010). The importance of empowering parents to be able to advocate for their children who have CCN has been well documented in the literature (Wang, Mannan, Psoton, Turnbull, & Summers, 2004). Empowerment is a strong predictor of positive parent outcomes relating to AAC (Minnes, Perry, & Weiss, 2015) and is an important aspect of family-centred practice (Nachshen & Minnes, 2005).

Service provision constraints. Most of the recommendations above are within the SLT's service capacity. However, there are many components of family support that are governed by outside policies and practices (Anderson et al., 2014). Inter-and-intra-agency coordination and the intensity and frequency of therapy available are some of the issues that SLTs are not able to change to better support families, without managerial support. In addition, some SLTs may be highly competent and want to work in a family-centred manner but are unable to do so, due to reduced service availability and caseloads of unmanageable size and complexity (Anderson et al., 2014).

Sibling training. Family-centred practice should ensure that the training needs of all of the family members are taken into account, not just the needs of the parents

or primary caregivers (Angelo et al., 1996). Involving siblings is an important aspect of AAC training for families and is likely to improve outcomes in communication and social skills (Linienfeld & Alant, 2005). Fisher and Shogren (2012) examined the degree to which the peers of children who use AAC have been involved in intervention and only 13 studies were found. They concluded that more research is required to understand how to support children who use AAC and their peers to develop relationships and communication skills as this is a socially valid method of providing AAC support.

Land and Clendon (2017) investigated the experiences and perceptions of siblings of children with CCN following a two-day AAC focused camp. The siblings increased their competence and confidence in the use of their brother's or sister's AAC system and their knowledge of communication partner strategies, such as expectant waiting, providing ALS and extending language. This study is one of the first of its kind and more research is needed to understand how best to support siblings of different ages to be involved in family-centred AAC training.

Effects of Group Intervention

The benefits of group intervention and peer-to-peer learning have been well researched in the field of psychology (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Haslam, Haslam, Jetten, Bevins, Ravenscroft & Tonks, 2010; Hedman, Lekander, Ljotsson, Mortberg, Hesser, Clark & Andersson, 2013; Maura & Weisman de Mamani, 2017). Some research has been completed in the wider area of SLT (Abrahamsson,

Millgård, Havstam, & Tuomi, 2017; Baron, Holcombe, & Van Der Stelt, 2018; Boyle, McCartney, O'Hare, & Forbes, 2009; Cantarella, Torretta, Ferruta, Ciabatta, Manfredi, Pignataro & Dejonckere, 2017; Elman & Bernstein-Ellis, 1999; Sommers, Schaeffer, Leiss, Gerber, Bray, Fundrella, Tomkins, 1966) and occupational therapy (OT) (Gauthier, Dalziel, & Gauthier, 1987), however little to no research has specifically explored the effects of group intervention for AAC intervention.

Benefits of peer-to-peer learning. Group intervention involves grouping children together to maximise the opportunities for learning and to gain positive outcomes associated with peer influence. Although there is very little research exploring this within the AAC field, several benefits of providing intervention within group settings have been identified. Peers can learn from each other. Peer learning is powerful as it harnesses the power of peer pressure for good (Hattie, 2009; Mitchell, 2014). Interactions with adults allow a child to learn language, whereas interactions with other children allow them to 'test' their newly learned language skills with support and scaffolding from adults (Wilkinson, Heibert, & Rembold, 1981). Children can practice social skills, such as turn taking, repairing communication breakdowns and communicating clearly, in real-world situations rather than just participating in role-play with an SLT. Peer-to-learning also supports generalisation, which is an important aspect of teaching language and social communication skills (Boyle et al., 2009).

Individuals who use AAC can provide emotional support and encouragement to each other within group settings. Individuals with CCN are at risk of mental illness (Ballin &

Balandin, 2007; Cooper et al., 2009a) and children who are in mainstream schools may feel isolated if they are the only person in their school and community who uses AAC. Offering groups where individuals who use AAC can develop and maintain friendships may increase confidence and self-esteem and 'normalise' their communication modality and disability. This may decrease the risk of later mental illness and feelings of dissatisfaction with life and disability services (Ballin & Balandin, 2007; Hamm & Mirenda, 2006).

Challenges of peer-to-peer learning. While the benefits of group intervention are numerous, there does not appear to be any research exploring the challenges of group-based intervention for children who use AAC. However, clinicians have identified some challenges that may mean it is not appropriate at all stages of the AAC journey. SLTs or teacher are likely to spend more time managing behaviours in groups (Krause, Bochner, Duchesne, & McMaugh, 2010), as opposed to individual therapy sessions. Children may be shy or less confident and reluctant to participate (Sheridan, 2012). Certain learning climates may be more facilitative to learning than others (Krause et al., 2010). For example, there are more distractions because there are more people in a room, therefore individuals who cannot cope with the increased visual, auditory and sensory distractions may not benefit from group therapy. Some children may require more time, than others, to find vocabulary on their AAC system or process language before they can reply (Beukelman & Mirenda, 2013). SLTs need to manage turn taking so that every child has time to talk, as is the case for group-based psychotherapy (Niec, Hemme, Yopp, & Brestan, 2005). Varying wait times for each

person in the group may make the SLTs job challenging as some children who use AAC will get bored waiting and others may not have had a turn before the group needs to move on to the next turn or topic (Beukelman & Mirenda, 2013).

Group mentoring. Another method of providing group therapy is for more experienced individuals who use AAC to mentor younger individuals who are new to using an AAC system. This relationship provides positive role models, teaches higher-level socio-relational skills and improves self-confidence for both the mentee and the mentor (Ballin, Balandin, Stancliffe, & Togher, 2012; Ballin, Balandin, & Stancliffe, 2013; Cohen & Light, 2000; Light et al., 2007). It is also likely to increase the desire to achieve well at school and personal and professional goals, as younger individuals who use AAC are inspired by what others have accomplished (Ballin et al., 2013; Light et al., 2007). SLTs in one study felt that collaborating with AAC mentors resulted in improved benefits for both the mentor and the mentee (Ballin, Balandin, Stancliffe, & Togher, 2011). Additionally, a review of several studies found good effect sizes for the learning achievements associated with peer tutoring for both the tutor and the tutee (Mitchell, 2014). Although these studies were related to children with disabilities or special education needs and not specifically individuals who use AAC, the results are promising for children who use AAC.

AAC Camps

Camps provide a natural and highly motivating context for intervention (Papaioannou, Evaggelinou, & Block, 2014). Camps have been used to support children with a variety

of speech and language needs (Lockman, Haynes, & Dobson, 1981; Pamplona et al., 2005; Patel, Bless, & Thibeault, 2010; Prathanee, Lorwatanapongsa Mkarabhirom, Suphawattjariyakul, Wattanawongsawang, Prohmtong, & Thanaviratananit, 2011; Prathanee et al., 2011; Quinn, Nowosielski, Kitchen, & Belfior, 2014) including children who use AAC and their families. Camps have the potential to provide a unique learning environment due to the intensity of the experience and the opportunities for connecting with others with similar needs.

There is a lack of research specifically around AAC camps. Only seven studies published in peer-reviewed journals in English have investigated this topic (See Appendix A for a detailed summary). The methodology, results and limitations of these studies will be discussed. The studies outlined in this review met the following inclusion criteria: 1) camp attendees were described as having CCN and using AAC (low and/or high tech), 2) intervention targeted AAC competency for individuals with CCN (referred to as campers) and/or their family members, 3) intervention was provided either in a live-in camp format or an intensive day-stay camp format, 4) campers were aged between 3 and 30 years old.

Camp format. The camps varied in duration and number of hours, as well as location. Four of the camps used a live-in style format. Three of these camps were 5 days long (Berger & Feucht, 2012; Bruno & Dribbon, 1998; Bruno & Trembath, 2006). One camp was described as lasting for one week (Mbangamoh, Perry, Powers, & Simunds, 2008); the exact number of days was not stated. Three studies used a day-

stay camp format. Of the day-stay camps, two (Dodd & Hagge, 2014; Kent-Walsh, Binger, & Manlani, 2010) provided intensive input over two weeks while the third (Myers, 2007) provided the intensive input over four weeks and also included follow up visits to school over the following six weeks.

The studies focused on a range of outcomes. Two studies (Berger & Feucht, 2012; Mbangamoh et al., 2008) provided narrative recounts of the experiences of the camp attendees. Bruno and Dribbon (1998) examined whether a parent-training programme combined with a camper-training programme would have positive effects on parental perceptions on AAC device use. Bruno and Trembath (2006) explored whether the campers' syntactic performance could be improved following a week of intensive input. Kent-Walsh et al. (2010) used a specific programme, the ImPAACT programme, to teach communication partners to facilitate the AAC skills of campers, while the other two studies (Dodd & Hagge, 2014; Myers, 2007) used general evidence-based practices (such as ALS) to enhance AAC use.

Camper information. An accurate and comprehensive description of participants is important for research consumers to be able to generalise the findings to other populations (Haynes & Johnson, 2009). There were between 9 (Bruno & Trembath, 2006) and 30 (Dodd & Hagge, 2014) campers at each of the camps. Campers were aged between 3 (Kent-Walsh et al., 2010) and 23 years (Berger & Feucht, 2012). Although, Mbangamoh et al. (2008) did not specify age and only stated that the campers were young adults aged 18 years and up.

While the majority of the campers were diagnosed with cerebral palsy (CP), individuals with other diagnoses, such as autism spectrum disorder (ASD), traumatic brain injury, Down syndrome and some rare syndromes also attended. Only four studies (Bruno & Dribbon, 1998; Dodd & Hagge, 2014; Kent-Walsh et al., 2010; Myers, 2007) provided gender information, showing that in general more males attended than females. The other studies (Berger & Feucht, 2012; Bruno & Trembath, 2006; Mbangamoh et al., 2008) referred anecdotally to both females and males attending.

Limited information was provided regarding the campers' physical, vision and hearing abilities and no information regarding ethnicity was provided for the live-in camps. Myers (2007) provided an excellent description of the campers' access methods, mobility, physical characteristics, speech, AAC device and language system. Two studies (Dodd & Hagge, 2014; Kent-Walsh et al., 2010) did not provide these details. Dodd and Hagge (2014), in contrast, recorded ethnicity data which none of the other studies provided. Bruno and Trembath (2006) stated that all of their campers used direct selection to access their AAC systems. There was some descriptive information about access methods in the other studies, for example, Mbangamoh et al. (2008) referred to the slow scanning speed of one camper. Three studies (Bruno & Dribbon, 1998; Bruno & Trembath, 2006; Mbangamoh et al., 2008) listed all of the high-tech communication devices that the campers used. Berger and Feucht (2012) mentioned that one of the campers used a Tobii device. None of the studies included information

about which language systems or page sets the campers used. The overall lack of camper information reduces the generalisability of the results.

Camp methods. These studies used a variety of methods of providing intervention to the camper and/or their families and also for measuring the effects of the intervention. The majority of the studies used an ALS type approach. For further information, refer to Appendix A.

Only some of the studies involved family members at camp (Berger & Feucht, 2012; Bruno & Dribbon, 1998; Bruno & Trembath, 2006; Kent-Walsh et al., 2010; Myers, 2007). The siblings were invited to attend only two of the camps (Bruno & Dribbon, 1998; Bruno & Trembath, 2006). Myers (2007) provided follow-up visits to the school team to provide training on what was covered at camp and to integrate these strategies into the school programme but none of the other studies included the school team.

Only two of the studies included AAC mentors. Myers (2007) reported that an adult who uses AAC came to the camp to provide advice and connection to the campers and their families. Berger and Feucht (2012) recounted that their camp was run by an AAC mentor who has a Master's Degree and was able to connect with all of the campers due to his shared experience.

All of the studies used a range of naturalistic contexts to promote AAC use, such as self-talk, ALS and expansion. There was variation in the comprehensiveness of the description of the intervention, therapy goals and resources, which limited the replicability for many studies.

Studies ranged on a continuum of structured to unstructured activities for teaching AAC. Mbangamoh et al. (2008) started each morning with unstructured time at “Camp Courage Coffee Shop”, where campers were able to practice ordering beverages, interacting socially and building new relationships. After this, however, there were structured discussions about certain topics, e.g., how to repair a communication breakdown. Kent-Welsh (2010) did not provide the campers with any structured AAC instruction during the camp activities but used ALS. However, in this study, the parents were explicitly trained on how to promote communication opportunities during shared storybook reading activities. The parents then participated in structured shared storybook reading with their child, using the training they received and were supported to refine their techniques. SLT students supported the families to participate in the activities. Bruno and Trembath (2006) focused on structured shared storybook reading and art activities, as the context for supporting and extending communicative competence. They provided examples of the communication displays they created for their therapy activities but did not provide a detailed description of intervention steps during the activities. Bruno and Dribbon (1998) provided parents with structured technical device operation training but also taught use of the AAC system within naturalistic unstructured interactions with their child.

The data collection methods varied between the studies. Berger and Feucht (2012) relied on the second authors' memory to recount what happened at camp and did not mention taking field notes. This is an informal method of recording information but resulted in a rich narrative. The authors shared quotes from the campers to convey a range of emotions and character changes in the campers. Bruno and Dribbon (1998) collected a pre-and-post camp and 6-month post-camp survey of how often AAC was available, how confident parents felt using AAC and parents' perceptions of their child's AAC skills. Three studies (Dodd & Hagge, 2014; Kent-Walsh et al., 2010; Myers, 2007) used surveys as well as pre-and-post camp language assessments to measure changes in AAC use. The results of the pre-and-post camp assessments were not detailed in the Dodd and Hagge (2014) study. Myers (2007) and Kent-Walsh et al. (2010) both provided detailed information about the pre-and-post camp assessments. However, only Kent-Walsh et al. (2010) reported treatment integrity and inter-rater reliability data, which were of an adequate standard. Bruno and Trembath (2006) administered a battery of pre-and-post camp assessments focused on syntactic competence.

None of the studies provided information on the amount of additional intervention, which may have occurred incidentally during other activities at camp. It would have been useful for these researchers to comment on the amount and quality of AAC use outside of the direct therapy activities. Overall, there was a lack of detail about the methods of intervention, data collection and analysis.

Camp results. All of these studies reported that campers benefited from attending camp. All of the campers, bar one in the study by Kent-Walsh et al. (2010), increased their AAC system use, the number of symbols combined and the range of language functions communicated. Most of the studies found that there was an increase in the complexity of messages produced by the campers and also an increase in the frequency of AAC use by adults using ALS following camp. Berger and Feucht (2012) recounted several quotes, such as “I don’t feel like an outcast” (Berger and Feucht, 2012, p. 82), which demonstrated that connecting with other individuals who use AAC developed a sense of belonging and was a powerful positive outcome of camp.

Appraisal. Making strong clinical recommendations from these studies is difficult. The general perception expressed within each study was that campers, parents and other stakeholders: 1) valued and enjoyed the camp experience, 2) perceived improved communication outcomes for the camper and the parents and 3) benefited regarding sociocultural outcomes, such as developing a sense of belonging and connecting with other individuals who use AAC and their families. This evidence is socially valid as it records the practical and real gains for individuals who use AAC and their families.

The overall internal validity of these studies was limited due to poor documentation of the research question, independent and dependent variables, and data collection and

analysis methods. The external validity of these studies was limited as participants were poorly described in most cases, the inclusion and exclusion criteria were not well defined and it was not clear how much intervention campers and their families had received previously or whether they had attended an AAC camp before, therefore it was not clear who may benefit from camp. There was a lack of maintenance and generalisation data, as only one study (Bruno & Dribbon, 1998) measured the long-term effect of camp by measuring parental perceptions of AAC use six months after camp. Bruno and Trembath (2006) mentioned that only two of the campers maintained the gains when they were back to school but there was no information provided about how or when this was measured. This means that there is limited certainty that the campers and their families maintained or generalised the skills learned at camp to other contexts over time. Myers (2007) commented that the benefits of camp were maintained six weeks after camp. However, this finding appeared to be anecdotal, as the assessments were not reportedly readministered six weeks after camp.

Methodological concerns limit the ability to draw strong conclusions of these studies, as there were variations in intervention goals, activities, intensity and outcome measures, and gaps in assessment and intervention documentation. However, the inability to confidently state that camp is an effective format to develop communicative competence is perhaps more related to the quantity and quality of the existing research, rather than the intervention itself.

AAC Camps and the New Zealand Context

The most prominent finding when examining the existing literature on the use of camps to develop the communication skills of individuals who use AAC was the lack of research. While an extensive worldwide list of camps can be found online (Prentke Romich Company, n.d.), only seven studies were found which investigated the effects of camp to provide AAC intervention and they were all from the USA. Considering that AAC camps have been run throughout the world for the past two decades, the lack of research is alarming.

In New Zealand, AAC camps are also used to provide AAC intervention and training to children who use AAC, families, school teams and others. KiwiChat Camp is an AAC camp organised by TalkLink Trust in New Zealand (TalkLink Trust, 2018a). The first camp was run in 2010 and they are run biannually (TalkLink Trust, 2018a). KiwiChat Camp is a 5 day residential live-in camp for school-aged students, their families/whānau and/or support people (TalkLink Trust, 2018a). Approximately 20 families attend each camp. The primary goal of KiwiChat Camp is for children who use AAC to improve their communication outcomes and for families to connect and learn from each other and the therapists/speakers. This is achieved through providing ALS and encouraging multimodal communication across environments and with a range of communication partners within families and between families.

Through my personal experience of KiwiChat Camps, as referred to in Chapter One, a number of issues were highlighted. The effectiveness of previous KiwiChat Camps has

been measured through post-camp surveys created by TalkLink staff, which parents, children who use AAC, TalkLink staff and volunteers complete. Parents were encouraged to ask their children to contribute to the survey and parents wrote their children's answers beside their own. Previous camp evaluations were typically extremely positive and indicated that families found camp highly beneficial regarding communication and sociocultural outcomes. The previous survey information supported the continuation of running camps and were used to make changes to subsequent camps, however more robust evidence was needed.

Several gaps in the international and New Zealand research have been identified relating to AAC camps. Therefore the current project has been planned to establish an evidence base relating to the use of camps as a means of providing AAC intervention for families. This project will: provide a New Zealand context, start to fill a gap in the research, help SLTs to understand how families experience and perceive camp and improve future camps. This project also aims to use methods that are more robust, than those of the camp studies discussed above, to ensure that this study results in robust clinical implications.

Chapter Three: Method

This chapter describes the methodological approach employed. The research question is presented and then the participant recruitment, data collection and analysis procedures are outlined. Finally, the ethical considerations and their management are summarised.

The Research Question

The intention of this research was to explore participants' experiences and perceptions of attending TalkLink's KiwiChat Camp. This research explored the following question: What are the experiences and perceptions of families (parents, siblings and children who use AAC) who attended KiwiChat Camp?

KiwiChat Camp 2016

TalkLink's biannual KiwiChat Camp was offered in 2016. The following information is known through my professional familiarity with KiwiChat Camp as a TalkLink SLT.

Approximately 100 people attended KiwiChat Camp. This included 18 families; TalkLink speech-language therapists (SLTs), occupational therapists (OT) and specialist teachers; and several volunteers including SLTs and OTs from the children's schools, and SLT and OT students who were in their final year of university. Specialist speakers who ran parent workshops also attended. Camp staff ran the outdoor activities, provided catering and supported with the accessibility of the environment.

TalkLink's criteria for attendance was that the child with CCN was aged between 5-21 years, s/he had an AAC system and at least one parent or caregiver and preferably siblings and/or extended family who were able to attend. TalkLink sent invitations to families they had previously worked with, whom they thought would benefit from the camp experience. Interested families were asked to complete an expression of interest form, and then TalkLink carefully selected the attendees to ensure that there was a balanced mix of families (e.g., children with a range of diagnoses and that there were at least two children who use AAC and siblings in each age group).

The TalkLink team designed and ran the camp programme as presented in Appendix B. The main theme for 2016 was Superheroes but as the camp ran over ANZAC day, some ANZAC themed activities were also included. The programme was designed for participation of the whole family, giving families time together and time where they were split into different groups. During the morning sessions, parents, whānau and adult support people attended workshops in which specialist speakers provided ideas on how to support AAC use at home and facilitated discussions about barriers and facilitators to AAC implementation. The siblings were split into groups with similarly aged children and participated in camp-style activities (such as BMX biking, abseiling, Frisbee golf, etc.) each day with their leaders. The children who use AAC participated in motivating activities, which provided multiple opportunities for ALS and using AAC. Examples included, superhero face painting, baking ANZAC biscuits, making ANZAC poppies, taking photos in the photo booth, reading stories, watching videos and playing interactive games.

In the afternoons and evenings, families participated in activities together and were supported by the TalkLink staff, volunteers and camp staff. Everyone had time each afternoon to practice his or her act for the show on the final night of camp. They also participated in outdoor activities, such as the hydro-slide, hot pool, playgrounds, flying fox, abseiling, watching movies, going to the river and had time together as a family relaxing. All meals were shared together and this was a time to connect and practice using AAC for functional reasons, such as commenting on the food or requesting more. Families were encouraged to have their child's AAC system with them at all times and TalkLink staff and volunteers wore core boards and other AAC systems at all times to ensure that ALS occurred across the day and across activities.

Participant Recruitment

In 2016, TalkLink Trust selected 18 families to attend KiwiChat Camp and 16 agreed to participate in the research project. Families were initially approached by the TalkLink Camp Organiser via a recruitment email with an Information Sheet and consent form inviting them to participate. Two Information Sheets were created: one for parents (Appendix C) and one for siblings older than 16 years, which used less complex wording (Appendix D). Two consent forms were also created. Parents signed a consent form (see Appendix E) indicating which parts of the study they were willing for themselves and their children to participate in and have audio recorded. Siblings older than 16 years signed their own consent form (see Appendix F). Everyone under 21 years was asked to give verbal assent before participating. A standard assent script

was created which is presented in Appendix G. Families were asked to email the consent forms to the researcher.

Positionality

Bias is a natural human characteristic. It is not possible for researchers to separate their background from the research process (Creswell, 2012). Therefore, in qualitative research, particularly inductive research approaches, it is important that the researcher describe their position in relation to the study (Gibbs, 2007). Researchers need to be conscious of how their experiences, skills, worldviews and personal values influence aspects of the study, such as data collection and interpretation, as well as the outcomes of the study (Creswell & Poth, 2017). Positionality aims to clarify the personal experiences that shape the research and ensure transparency of the reflexivity that informs the analyses and clinical implications (Creswell, 2014b).

Without contextualising the researcher and research setting, the meaning of the research may be lost (Creswell, 2014b; Gibbs, 2007). Positionality does not undermine the validity of the research, but rather it outlines the boundaries within which the research was produced and may be applied (Creswell, 2014b). Positionality informs the research study, rather than invalidates it, as personal perspectives and social viewpoints are specified (Creswell & Poth, 2017; Gibbs, 2007).

It is, therefore, necessary to identify and present my world-view and experiences in relation to this study. As stated in Chapter One, I work for TalkLink as an SLT and have been involved in KiwiChat Camp twice at the time of KiwiChat Camp 2016. My previous

observations of the experiences of families at KiwiChat Camp and knowledge of the limited research around camps, propelled me to complete this study. My beliefs and experiences of KiwiChat Camp undoubtedly influenced my interpretation of the data. To situate myself within this study, disclosure of my role was made clear to participants and all data analysis codes were regularly checked by my supervisors. Throughout the study, particular effort was made to remain self-aware of my involvement, and to ensure that my positioning and resulting effects were considered and made explicit.

Methodological Approach

This project used a combination of survey and interview methodology. Both of these are useful methods for gathering information about people's experiences and perceptions (Atieno, 2009). The parents were surveyed before and after camp and three parents participated in follow up semi-structured interviews within four weeks of camp. The siblings were interviewed in focus groups on the final morning of camp using a semi-structured format. The children who use AAC completed a survey on the final morning of camp. Five data collection instruments were developed for this project. See Table 1 for a summary of these.

Table 1

Data Collection Methods

Instrument	Format	Time point administered
Parent survey	Electronic Survey Monkey or paper based	Before camp
Parent survey	Paper-based	Final morning of camp or within 4 weeks of camp
Parent interview	Telephone interview	Within 4 weeks of camp
Survey of children who use AAC	Paper-based	Final morning of camp
Sibling interview	Group interview	Final morning of camp

Surveys. Surveys were chosen for several reasons. They can include a range of question types including more quantitative questions, such as multiple choice, rating scale, or Likert scale questions, as well as more qualitative open-ended questions. Surveys are a cost-effective method of gathering data compared to other methods, particularly online surveys which do not involve printing or postal costs (Ponto, 2015). Surveys are flexible, allowing participants to fill them out when they have time (Singleton & Straits, 2009). They are reported to be less intimidating when the participant has no rapport with the researcher and therefore the answers tend to be true expressions of the participant's thoughts and opinions (Check & Schutt, 2012). In this project, the researcher had built rapport with a few families through the TalkLink assessment service and therefore surveys were felt to be an effective means of gathering true reflections of the families' opinions. Surveys provide a straightforward method of comparing results across the population, but also over time (Check & Schutt, 2012). Therefore these results may be compared to future camps.

Interviews. Interviews were selected for this study because they allow for immersion into the context being explored (Punch & Oancea, 2009). Interviews also complement and add to the data gathered from surveys, as they explore the same questions about experiences and perceptions in more depth (Creswell, 2014a). The strengths of interviews are that they occur in natural settings, which increases the possibility of understanding non-obvious issues; they allow for rich, holistic and complex data collection; and focus on lived experiences whereby underlying issues are often brought to light (Atieno, 2009; Punch & Oancea, 2009; Singleton & Straits, 2009).

In this project, the interviewees chose a time for the interview when they would be at home and their child would be taken care of, therefore ensuring a safe and natural context for the interview. Using an interview rather than only a survey allowed the researcher to explore sensitive topics in a compassionate manner, which provided the participants with a safe space to express themselves in detail. The researcher had built rapport with all of the interviewees during camp and ensured that they understood that they could talk to someone else about the content of the interviews if they became upset about any of the topics. The interview questions were sent to the interviewees before the interview, to give them time to think about their answers and so that they were prepared for any emotional responses that may occur due to the sensitive nature of talking about their child who has CCN. Using interviews also allowed the researcher to adapt as new information emerged, which is not possible with stringent quantitative designs (Atieno, 2009). The researcher was able to use

probing comments to obtain more information about topics and to clarify unclear responses (Singleton & Straits, 2009). Although telephone interviews do not allow the researcher to read non-verbal cues (Ponto, 2015), many emotions can be detected via tone and pauses in conversation.

The voice of children who use AAC. Several international and national policies outline the importance of supporting children with CCN to be actively involved in the development of services designed to support them. Article 19 of the Universal Declaration of Human Rights (1948) sets out the right of all people to express opinions and ideas, but it is especially pertinent for children with CCN who face challenges in understanding and expressing themselves through spoken or written means. Additionally the United Nations' (1989) Convention on the Rights of the Child specifically focuses on children's rights to express themselves in all contexts. This is again supported by the Convention on the Rights of Persons with Disabilities (United Nations, 2006), which outlines strategic directions for enhancing people's participation in society.

Within New Zealand, the importance of the voice of people with CCN is highlighted by the current Disability Strategy (2016) and also by the principles of New Zealand's Treaty of Waitangi (1840); partnership, participation and protection. Ensuring that children's voices are heard is also a key focus of the New Zealand Children's Commissioner (2017). There is strong support for children with CCN being involved in

decision-making that affects them and their whole of life achievements (Doell & Clendon, 2018).

There are very few studies exploring the voice of children with CCN on communication intervention (Doell & Clendon, 2018). The research that is available recommends that creative and alternative methods be used for children to share their opinions, such as symbol based questionnaires (Doell & Clendon, 2018), as children with CCN have difficulty with understanding and expressing their opinions on topics such as service delivery, therapy goals and communication intervention. One resource which is actively engaging individuals with CCN in communicating their opinions and decisions is the Supported Decision Making project run by Auckland Disability Law (2016). This resource could be adapted for exploring the voice of individuals who use AAC in the future. This project used symbol based surveys (see example in Appendix K) and adapted ideas from the Supported Decision Making project to ensure that the children who use AAC were able to have their say about KiwiChat Camp and make recommendations for future camps.

Triangulation. One method of ensuring that the voices of children who use AAC are heard along with their family members is through triangulation. This involves comparing and contrasting the voices of children and their team members, such as parents, educators, therapists and extended family (Merrick & Roulstone, 2011). Data triangulation increases the validity of the analysis and interpretation of the data (Kisely & Kendall, 2011). When the different voices are combined, they create a more holistic

view of which aspects of therapy are perceived as important and how SLTs can best support each individual within the family and wider team (Yin, 2014). Using two datasets to cross verify, tests the consistency of the data, provides more insight into a topic and ensures that the results and clinical implications are rich, robust and comprehensive (Gibbs, 2007). In this study, triangulation was achieved by integrating the data from the surveys and the interviews.

Instrument Design and Procedures

Overview of instrument development. The surveys were adapted from those that TalkLink had used for previous KiwiChat Camps. The researcher also contacted organisers of AAC camps from overseas to ask about their feedback methods and data collection instruments. However, most of the organisations did not reply and the two who did, reported that they did not use formal feedback instruments at the end of their camps.

Both web and paper-based surveys were used in this study. The web-based pre-camp survey was selected as it is an efficient, low-cost way to distribute the questions and gather them when participants are located across a geographically dispersed population (Dillman, Smyth, & Christian, 2014; Singleton & Straits, 2009). A disadvantage of web-based surveys is that some families may have limited internet access or feel too busy to respond when at home due to the time pressures of their families. There may be technological problems with web-based surveys (Creswell, 2015). Due to these concerns, paper-based surveys were also offered at camp (Check

& Schutt, 2012). Paper-based surveys were used at the end of camp as WIFI was limited and therefore filling in online surveys was not practical.

The semi-structured interview guides (see Appendix) were created based on questions asked in previous research (Bruno & Dribbon, 1998; Dodd & Gorey, 2014; Kent-Walsh et al., 2010; Myers, 2007) and on the researcher's knowledge of AAC implementation. Telephone or Skype interviews were offered as it would have been costly in time and money for the researcher to visit each family for a face-to-face interview.

TalkLink's General Manager, who had been involved in all previous KiwiChat Camps and the TalkLink Board of Trustees Māori advisor, reviewed the instruments. They checked that the surveys were an appropriate length, covered the depth and breadth of the camp experience, were worded appropriately for each participant group, and were culturally sensitive.

The content, format and data gathering process pertaining to each of the participant groups will now be described.

Data collection for parents.

Content. Both the pre-and-post camp surveys asked parents about their confidence in supporting their child who uses AAC, where and what they learned about AAC, and how much they used AAC at home. In the pre-camp survey, parents were asked about their expectations for camp and how connected they felt to other families

of children who use AAC. In the post-camp survey, parents were asked whether their camp expectations had been met, whether they felt more connected to other families, and whether they found it useful interacting with the mentors who use AAC. In the post-camp survey, parents were also asked to discuss their experiences at camp, whether the activities were appropriate and whether they found camp beneficial. This survey also explored their perceptions about the parent workshops, whether their knowledge and skills about implementing AAC had changed and whether they had any suggestions for future camps. Please see Appendix H and I for the full surveys.

The researcher conducted the semi-structured interviews and audio recorded them on her mobile phone. Relationships had been established with all of the interviewees during KiwiChat Camp. In the interviews, the three parents were asked questions, which narrowed in focus from their general experience of having a child who use AAC to specific aspects of KiwiChat Camp and what impacted them the most. Semi-structured interviews were used as they provided a framework of pre-established questions to be asked but also ensured that the interviewees had the flexibility to answer these as they saw fit (Punch & Oancea, 2009). This method allowed the interviewer to use many techniques, such as sensitive silence, prompts, clarifying questions and active listening, to explore the interviewee's interpretations of camp experiences (Punch & Oancea, 2009).

The semi-structured interview questions were open-ended and required the parent to describe their experiences and whether they perceived any benefits in attending

KiwiChat Camp. They were asked whether they had met others who use AAC before coming to camp. They were also asked to identify positives and challenges in implementing AAC, and to describe their experiences of using AAC in the community. The more specific questions explored certain aspects of the camp experience, such as networking with other families; interacting with mentors who use AAC; attending training sessions; and seeing AAC 'in action' across activities and with a range of communication partners. The final questions asked what they would tell their friends/family/colleagues about camp and whether they would like to attend KiwiChat Camp again if they were offered the opportunity. See Appendix J for full interview questions.

Format. The pre-camp survey contained eight Likert questions and four short answer questions. The post-camp survey contained 17 Likert scale questions and 11 short answer questions. The Likert scale used a 6-point rating scale (strongly agree, agree, neutral, disagree, strongly disagree, not applicable). Both surveys took approximately 30 minutes to complete. The interview guide contained 12 questions and took approximately 30 minutes.

Process. After families returned the consent forms, a Survey Monkey link to the pre-camp survey was distributed via email. If parents did not complete the online survey, they were provided with a paper copy on the first day of KiwiChat Camp. TalkLink request that all families fill in a post-camp survey to assist with planning future camps. Post-camp surveys were distributed in paper form on the final day of

KiwiChat Camp by the researcher to families who had agreed to participate in this project. Families who were unable to complete the survey on the final day of camp were asked to email a PDF copy to the researcher within four weeks of the end of camp. Post-camp surveys were distributed to families who did not agree to participate in this project by the Camp Organizer. Families were made aware in the Information Sheet and consent form that TalkLink would have access to the anonymous post-camp survey data.

In the pre-camp survey, parents/caregivers were asked whether they would be willing to participate in an interview after camp. Eight parents/caregivers agreed to participate, and three were randomly selected. Within four weeks of returning home from camp, the three parents participated in a follow-up semi-structured interview via telephone with the researcher, who was also a leader at KiwiChat Camp. Skype was offered but none of the parents chose this option. Parents were given a choice of time and day by the researcher. The interviews were digitally recorded and transcribed by the researcher.

Data collection for children who use AAC.

Content. The children who use AAC completed a survey on the final morning of camp about their camp experience. The questions asked whether they liked camp; whether the activities and the show were enjoyable; whether they learnt more about using their AAC system, and whether they would like to use their AAC system with a range of communication partners when they went back to their schools and communities. One of the questions asked whether they would like to come to KiwiChat Camp again if they had the opportunity. See the survey in Appendix K.

Format. The survey contained nine Likert scale questions, which had three answer options (“agree, I’m not sure, disagree”). Both the question and the answer options were paired with visuals to the support the receptive language and emergent literacy skills of the children. The final question was open-ended and asked, “anything else you want to tell us about”. Filling in the surveys took no more than 20 minutes.

Process. The SLT students distributed surveys on the final day of camp. Some of the children had emergent literacy skills and others were not able to physically hold a pen and fill it out. Therefore the SLT students supported them to complete the survey. The SLT students received brief training from the researcher before administering the surveys to ensure that they only provided support to read the questions and write the answers but did not influence the children’s answers. The SLT student marked the level of support the child required to complete the survey at the end of the document, e.g., “independent” “verbal prompt”, “visual prompt”.

Data collection for siblings.

Content. The school-aged siblings were asked to participate in a focus group semi-structured interview with similarly aged children. All of the questions were asked using simple syntactic forms. The siblings were asked open-ended questions about their experiences of having a sibling who uses AAC, their confidence in using AAC, and their experiences while at camp, e.g., what they learned about AAC and which activities they enjoyed. They were also asked about their thoughts on meeting other families and mentors who use AAC and how this affected their confidence in supporting their brother or sister to use AAC. The final questions asked what they would tell their friends about KiwiChat Camp when they went home and whether they would like to come back if they had the opportunity. See Appendix L for full interview questions.

Format. One of the advantages of focus groups is that they allow participants to reflect on each other's opinions which enhances engagement and the quality of the data (Kisely & Kendall, 2011). The semi-structured format of the interviews meant that the researcher was able to facilitate discussion and interaction between the siblings, as well as probe unexpected topics or opinions (Punch & Oancea, 2009). The children were asked 12 questions and the interviews took approximately 30 minutes.

Process. On the last full day of camp, the researcher conducted focus group interviews with the siblings within their camp groups with their group leader present.

The researcher had built relationships with all of the siblings during camp. Their group leader was present for these interviews to ensure the siblings felt at ease, as they were very comfortable with their leader after spending five days together. The group leaders did not participate in the interviews but used non-verbal active listening skills (such as nodding, eye contact and attending to what each child was saying) and brief verbal affirmations (such as “I see”, “oh right” and “thanks for sharing that”) to encourage the siblings in their group to share information with the researcher.

Data Analysis Framework

The quantitative data from this project were analysed using descriptive statistics. The qualitative data were analysed using a general inductive approach (GIA) (DeCuir-Gunby, Marshall, & McCulloch, 2011; Thomas, 2006).

Quantitative data – Likert questions. The data from the Likert questions were reported using descriptive statistics: median and mode.

Qualitative data – open-ended survey data and interview data. The open-ended survey data and the interview data were analysed using GIA (Thomas, 2006). This approach is commonly used in qualitative SLT research (Ball, Müller, & Nelson, 2014; Thomas, 2006). The purpose of using an inductive approach is to a) develop a framework to describe the main themes evident in the raw data, b) establish clear links between the research questions and the summary findings and c) condense raw data into a brief and summarised format (Kisely & Kendall, 2011; Thomas, 2006). This

approach can be used to produce reliable and valid findings (Punch & Oancea, 2009) and provides a straightforward way of deriving findings that emerge from the data rather than testing data with previous assumptions or theories (DeCuir-Gunby et al., 2011; Punch & Oancea, 2009; Thomas, 2006).

In using GIA, the transcribed semi-structured interviews and the short answer questions from the surveys were read several times (Punch & Oancea, 2009; Thomas, 2006). Rigorous and systematic reading of the raw data allowed major themes to emerge (DeCuir-Gunby et al., 2011). Coding was performed using tables in Microsoft Word. Each section of the survey and interview transcripts were broken down into meaningful units of text and assigned a label, called a code (DeCuir-Gunby et al., 2011). Codes were considered meaningful when they related directly to the research question. Some sections of text were coded into more than one category, while other sections were not assigned to any category as they were not relevant to the research question (Punch & Oancea, 2009; Thomas, 2006). For example, parents talked about aspects of life outside of camp. However, these were not included as they were not relevant to the perceptions and experiences of attending KiwiChat Camp.

Regular meetings with both supervisors were held to refine the codes and their definitions to finalise the codebooks. The codebook for the sibling data is available in Appendix M. The codebook for the parent data is available in Appendix N. Data from parent surveys is displayed in blue text and data from the parent interviews is displayed in black text, to clearly identify where the information originated from.

After the codebooks were completed, the codes were sorted into groups with other similar codes to arrive at themes. Codes that did not apply directly to the research question were discarded. Data from the parent post-camp surveys and interviews were combined using the process of triangulation, to ensure that themes were discreet but broad enough to capture the meaning behind each section of text. The final themes allowed the researcher to share the families' experiences in a structured way and emphasise the interconnectedness of the families' experience. Table 2 shows how the codes were grouped into themes. This visual representation of the themes and codes was reviewed again to ensure that the final theme was the correct interpretation of the data. The codes were grouped and collapsed into "organising themes" where there were several codes which related to a similar theme (Thomas, 2006). These organising themes were then grouped into broader categories, labelled "global themes". There is no hierarchy of themes as they explore social phenomena rather than hypothesis testing (Ball et al., 2014; Kisely & Kendall, 2011; Seidman, 2013).

As previously stated, the analysis (such as, decisions about coding and interpretation of relevant themes) may be influenced by my positionality as the researcher, as findings are shaped by the assumptions and experiences of the researcher and what is deemed to be more or less important (Gibbs, 2007; Seidman, 2013; Thomas, 2006). This possibility is minimised as the findings arise directly from analysis of the raw data rather than from pre-constructed models, expectations or theory-driven codes (Gibbs,

Table 2

Example of Coding and Data Analysis Process for Parent Data

Global Themes	Organising Themes	Codes
Emotional response	Motivating	Motivating
	Inspiring	Inspiring
	Empowering	Empowering
	Overwhelming	Overwhelming
Communication outcomes	Increased knowledge	Technical Skills
		Aided language stimulation
		General awareness of AAC
	Increased expectations	Increased expectations
	Increased AAC use	Increased AAC use
Sociocultural outcomes	Connections	Increased confidence of child who uses AAC
		Increased confidence of family
		Connection with other families
		Connection with other children who use AAC
	Connection with mentors	
	Enjoyment	Enjoyment
	Developing identity	Developing identity
Sense of belonging	Sense of belonging	

2007; Punch & Oancea, 2009; Thomas, 2006). They were also minimised through discussions with both supervisors to check each level of analysis.

Ethical Considerations

Trustworthy research is established upon sound ethical principles. This research project involved gathering information from children, including some with CCN. The

Massey University Human Ethics Committee gave ethics approval (see Appendix O) before families were approached by the Camp Organiser. This section will outline the six main ethical issues pertaining to this project.

Informed consent. Participation in research should always be voluntary and be completed with a thorough understanding of what the research involves and how the information will be used (Gibbs, 2007; Massey University, 2016). Therefore, comprehensive and clear Information Sheets were provided to parents and older siblings before they signed consent forms, and verbal assent was obtained from all of the children who use AAC and their siblings.

Conflict of interest. The camp was run by TalkLink. The General Manager of TalkLink gave permission for this project to take place. All of the potential participants were associated with TalkLink. Therefore, families may have felt pressured to participate. One family was currently working with the researcher in her capacity as a TalkLink SLT. To alleviate this pressure, the researcher stated in the Information Sheet that participation or non-participation would not impact on any services the family receives from TalkLink now or in the future.

Risk of harm. It is unethical to expose participants to unnecessary harm, which includes causing emotional distress or being cultural insensitive (Gibbs, 2007; Massey University, 2016). Therefore, the researcher made every effort to identify and minimise potential harm. The risk of becoming upset while talking about emotional

topics was mentioned in the Information Sheet and acknowledged at the end of the surveys/interviews. The researcher planned to suggest that families talk with a support person (e.g., family member, general practitioner or TalkLink SLT) if they were upset, however, no one became noticeably upset during the interviews or surveys. The researcher consulted with TalkLink's Māori advisor to ensure cultural and emotional safety around the project.

Privacy and confidentiality. Participants were de-identified on documents and their names were not revealed during the analysis or presentation of findings. All information gathered was stored securely on a password-protected computer. Consent forms and the code document were stored separately from the other data. Emails from the participants were deleted upon receipt, following action. All survey data and audio files were transferred for safekeeping to the supervisor directly following analysis and will be held for five years after collection. All attendees completed TalkLink's Confidentiality Agreement (see Appendix P). Siblings were not expected to complete confidentiality agreements or transcript release forms, as it was not feasible to expect them not to talk to their family about the interview, however they were asked to remember to respect one another during and following the interview process.

Access to data. All KiwiChat Camp attendees were invited to fill out the post-camp survey by TalkLink staff to assist with planning for future camps. Therefore, if attendees decided not to be involved in this research, the post-camp survey was only

distributed/collected by the Camp Organiser, and not by the researcher. The fact that TalkLink would have access to the anonymous post-camp survey data was made clear in the Information Sheet and consent forms.

Non-participation. The Information Sheet stated that participants could withdraw at any time. If parents had not permitted their children to participate in the research, then another activity was organised for them while the surveys/interviews were taking place. The families who did not participate in this project did not have siblings at camp. Therefore an alternative activity was not required. TalkLink's post-camp survey was distributed to the families who did not participate in this research but did not fill these in or hand them in.

Conclusion

This chapter outlined the rationale for the methodological approach used to explore the experiences and perceptions of families who attended KiwiChat Camp. The research question was stated and the methods of data collection and analysis were described. Key ethical issues for research pertaining to vulnerable children was discussed, ensuring that each individual involved in this study was safe. The results from the project are presented next.

Chapter Four: Results

The purpose of this study was to explore the perceptions and experiences of families who attended KiwiChat Camp 2016. The results from the parents are presented first, followed by the results from the children who use AAC and finally the results from the siblings. The findings for each of these participant groups emerged from analysing the quantitative data using descriptive statistics and the qualitative data using a general inductive approach as per the procedures outlined in the methods chapter.

Participant Information

Eighteen families attended camp and 16 of those families agreed to participate in this project. All 16 parents completed the pre-camp survey but only 15 parents and 13 children who use AAC completed the post-camp survey despite reminders via post and email. The children who use AAC and their siblings were aged between 5 and 21 years. The families came from a range of socioeconomic backgrounds and cultures, including Māori, New Zealand European, Pacific Island and other cultures. Roughly equal numbers of males and females attended. See Table 3 for more information.

Findings – Parents

The results from the parent pre-camp surveys, post-camp surveys and interviews are presented in this section. The parents' expectations before coming to camp are outlined first to provide a context for the results. Themes relating to the parents'

Table 3

Demographics of Children who use AAC

ID	Age	Gender	Diagnosis	Communication system	Access method	Ethnicity	Family attending with them
1	5	F	CP, bilateral hearing loss	Accent1000 with Unit60 sequenced and 112 symbol core board with fringe vocab	Direct	NZ European	Mum
2	6	F	DS	iPad with TouchChat WordPower and 77 symbol core board with fringe vocab	Direct	NZ European	Mum, Dad, sister
3	6	M	CP	iPad with TouchChat WordPower and 77 symbol core board with fringe vocab	Direct	Filipino	Mum, Dad, sister
4	6	M	Chromosome abnormality, ASD	iPad with TouchChat WordPower and 77 symbol core board with fringe vocab	Direct	Cook Island Māori/German	Mum, Dad, brother
5	7	M	Angelman syndrome	iPad with TouchChat WordPower and 77 symbol core board with fringe vocab	Direct	Indian	Mum, Dad, baby
6	8	M	CP	TobiiI12 with WordPower	Switching	Fijian	Mum, aunty, cousin, cousin

7	9	M	DS	iPad with TouchChat WordPower and 77 symbol core board with fringe vocab	Direct	NZ European	Mum, Dad, sister, sister, brother
8	9	F	Chromosome abnormality	iPad Mini with TouchChat WordPower and 77 symbol core board with fringe vocab	Direct	NZ European	Mum, grandma, grandpa, brother, sister, sister
9	9	M	CP	Surface Pro with Compass 15+PODD student setup and 20 symbol PODD book	Head mouse, partner assisted scanning	NZ European	Dad
10	10	M	CP	Accent1000 with WordPower and alphabet chart	Direct	NZ European	Mum, Dad
11	11	F	RETT syndrome	Tobii PCEyeMobile with Susan Norwell RETT setup	Eye gaze	NZ European	Mum, brother
12	11	F	CP	Surface Pro with Tobii Communicator 5		NZ European/ Chinese	Mum, Dad, sister
13	13	F	CP, epilepsy	Tobii PCEyeMobile with WordPower	Eye gaze	Māori, NZ European	Mum, Dad, sister
14	13	F	Chromosome abnormality	One page opening PODD 12 symbol per page	Direct	NZ European	Mum, Dad, brother, brother, sister

15	15	F	DS	iPad with Proloquo2go and 77 symbol core board with fringe vocab	Direct	NZ European	Mum, Dad
16	16	M	ASD, DS, ADHD	iPad with TouchChat and 77 symbol core board with fringe vocab WordPower	Direct	Dutch/Māori	Mum, sister, brother in law, nephew, other family member

Note. CP = Cerebral palsy, DS = Down syndrome, ASD = Autism spectrum disorder, ADHD = Attention deficit disorder

perceptions and experiences of attending and participating in camp are then presented. To manage the wealth of parent data, and avoid duplicating the discussion of key outcomes, the quantitative and qualitative results are reported together, with the themes arising from the qualitative data analyses used as guideposts to structure the presentation of findings. The quantitative data from the pre-camp and post-camp surveys are also provided separately in Tables 4 and 5.

Expectations. The information in this section captures the parents' expectations before camp and thus provides a context for understanding their engagement in camp and their perceptions and experiences in the thematic analyses that follow. The parents came to camp with a variety of expectations, most of which were met and exceeded. However, some were unfulfilled and several came as a surprise. Their pre-camp expectations will be discussed in this section and how their expectations were met will be discussed within the theme it relates to in the following sections.

The open-ended pre-camp survey questions related to parents' expectations of KiwiChat Camp. Overall parents expected to enjoy camp and have a "fun family time with other families and new friends." Some parents had never had the opportunity to take their child with CCN on a camp before. This was highlighted by one of the parents: "We are all looking forward to the camp also because this is the first camp S has been to." Additionally, parents were "really looking forward to camp" because "the whole

Table 4

Pre-camp Survey Likert Responses from Parents

Questions	Response					
	Not answered	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1 I feel confident in using my child’s communication system			4	3	8	1
2 I feel confident in creating opportunities for my child to communicate		1	4	6	5	
3 I feel confident in programming/editing my child’s communication device	2	1	2	5	6	
4 I feel connected to other families of children who use AAC devices	2	3	7	2	1	
5 I feel confident in prompting my child to use their communication device	1		5	4	6	
6 My child needs support to learn to use their communication device		1		1	5	9
7 I feel confident with modelling language on my child’s communication device		1	5	3	7	
8 I have interacted with older children or adults who use communication devices	2	5	5	4		

Note. Mode responses are indicated in bold. Median responses are underlined.

Table 5

Post-camp Survey Likert Responses from Parents

	Questions	Response				
		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	My goals/expectations for the camp were achieved		1	4	<u>5</u>	5
2	The camp activities were appropriate for my child			1	<u>10</u>	4
3	My child enjoyed the camp experience				6	<u>9</u>
4	The camp experience was helpful to our family				<u>8</u>	7
5	I feel that my child/children were safe at camp				5	<u>10</u>
6	My child's confidence in using his/her communication device improved		1	5	<u>5</u>	4
7	My child gained more confidence in initiating communication using his/her communication device		1	5	<u>6</u>	3
8	My child improved his/her ability to maintain a conversation using his/her communication device			<u>9</u>	5	1
9	I feel more confident in my ability to help my child communicate			3	<u>6</u>	6
10	I feel the camp experience provided me with tools to help my child become a better communicator			1	<u>8</u>	6
11	I am satisfied with the camp experience			1	6	<u>8</u>

12	The parent workshops in the morning were useful and I gained knowledge and confidence because of them		3	4	8
13	The parent group trainers/therapists was skilled in facilitating group discussion		2	<u>7</u>	6
14	Networking with other families who have a child who uses a communication device was useful			6	<u>9</u>
15	I feel more connected with other families (compared to before I came to KiwiChat Camp) and will continue these connections	1	1	<u>9</u>	4
16	Interacting with the AAC Mentors was useful and I gained knowledge from them		2	<u>7</u>	6
17	I would send my child to this camp in the future, if I had the opportunity			4	11
18	I would recommend KiwiChat Camp to a friend whose child uses AAC			5	10

Note. Mode responses are indicated in bold. Median responses are underlined.

family is involved". One parent stated that he was "not sure" about the camp experience and that he had "never been and not sure what to expect."

Information from the pre-camp survey showed that parents expected to have a positive response to camp. They expected the whole family to feel more confident using AAC. For example, one parent answered the question: "What are your goals for camp?" with "Go home feeling confident using the device and J being happy to use it!" Motivation was another common emotion parents expected to feel, exemplified by this statement "I expect that our knowledge of the device will improve and that we will be more motivated to use it." A few parents also expected their child who uses AAC to feel empowered through seeing other individuals who use AAC. One example of this was, "For M to make a connection with the significance of how useful his Talkie can be and want to use it more frequently."

A common expectation, in the pre-camp survey, was for the whole family to make connections with other families who use AAC. One parent reported that she wanted her child "to connect with other campers using a Talker like him" and another parent stated that they hoped to "interact with other parents and hear their experiences and successes" and for "siblings to be more relaxed around others with a variety of disabilities and to see devices as normal in other families."

All of the parents expected to gain a better general understanding of AAC and most wanted to increase their technical skills and had some specific goals, such as learning “how to back up his device which I am currently unable to do” and learning “more about programming and editing on her eye gaze.” A few (n=6) parents mentioned wanting to learn more about ALS, for example saying “to learn how to integrate use of the AAC device in everyday situations.” Two parents specifically mentioned hoping that the siblings would learn more about AAC and ALS. One parent said she would like “J to learn how to use TouchChat so he can model for his brother.”

Perceptions and Experiences. The qualitative analyses of the open-ended post-camp survey questions and the three post-camp interviews revealed three global themes along with several organising themes. These were: emotional response (motivating, inspiring, empowering, overwhelming), communication outcomes (increased AAC use, confidence, expectations, knowledge) and sociocultural outcomes (enjoyment, connections, sense of belonging, developed identity). These themes are presented in Figure 1, which has been colour coded according to where the data was sourced. The black themes emerged from both the survey and interview data. The blue themes emerged from the survey data only and the green themes emerged from the interview data only. As explained earlier, these themes have been used to organise the presentation of both the qualitative and quantitative findings in this section.

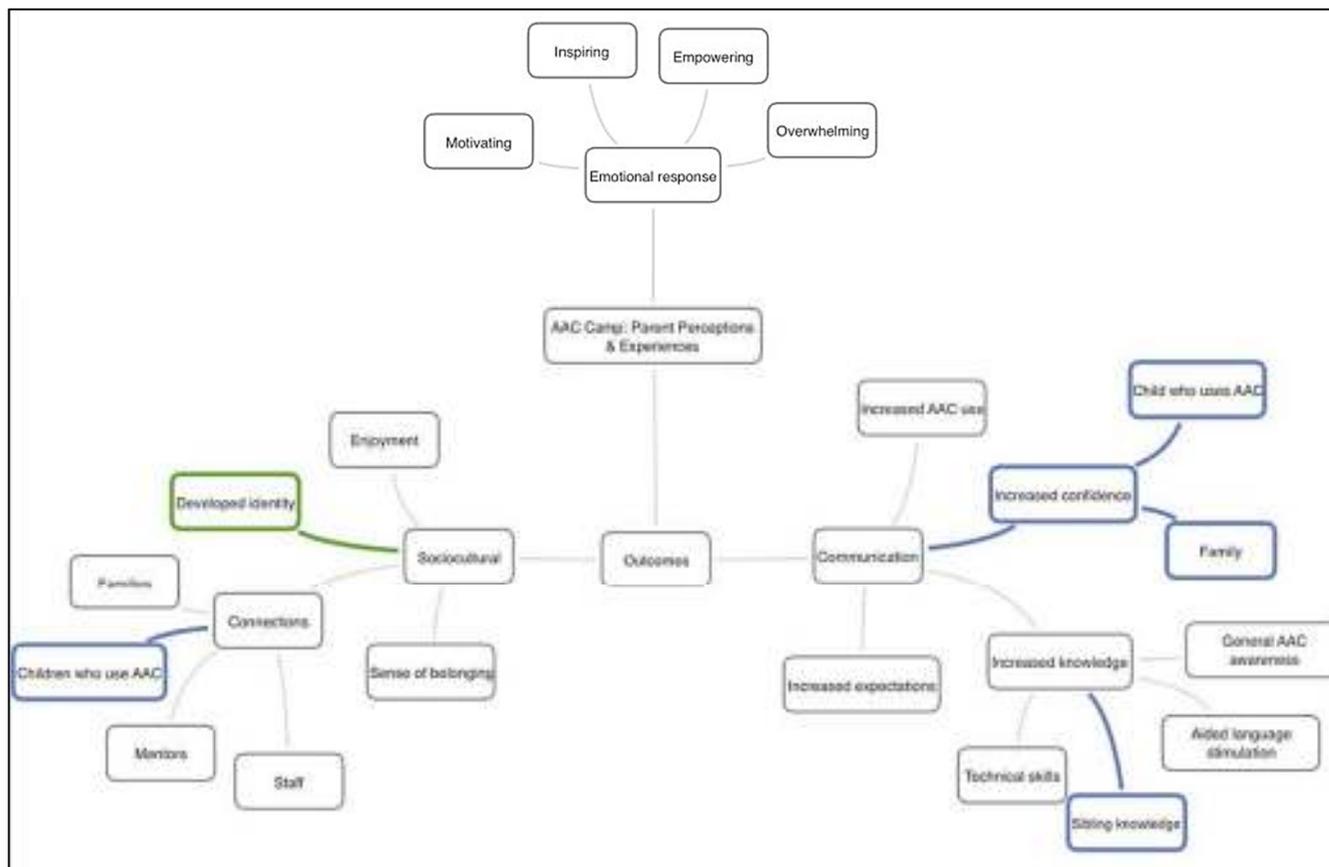


Figure 1: *The Experiences and Perceptions of Parents of Children with Complex Communication Needs about Attending KiwiChat Camp: Themes*
 Note. Blue themes result from survey data only. Green themes result from interview data only. Black themes result from survey and interview data.

Emotional Response. Many of the parents wrote about their emotional response to camp in the surveys and the three parents spoke about this at length throughout their interviews. In the surveys and interviews, parents talked about feeling motivated, inspired, empowered, and overwhelmed. In the interviews, one of the questions asked about whether they felt their confidence had increased, however, parents did not speak about confidence but rather inspiration, motivation and empowerment. For example, when asked, “Do you feel more confident in supporting M with his device?” one parent answered “Absolutely!” but then went on to talk about how empowered she felt to tell others about AAC.

Motivating. Increased motivation was a common theme across the surveys and interviews. Eight parents commented on this in the surveys, with one saying “My motivation and belief in AAC is stronger than ever before” and another parent said that they now have “motivation to continue to try to get her to use it.” In the interviews, all three parents talked at length about how camp increased their motivation to implement AAC in their everyday lives and also to try and get other team members ‘on board’ with using AAC. For example, one mother said “it did motivate us to use it [AAC device] more. Yes, we use it every day now.”

All of the parents who were interviewed discussed the difficulty of motivating their children who use AAC before and after camp. For example, one parent said “I find it very difficult to motivate him... and he still doesn't get how it is helping him or how it could help him” while another parent shared that:

Sometimes M is still do-dally and he still just goes tap tap tap and I just go 'oh well'.

It's one of the things that mentor said; it's the device user that has to want to use it.

And that if, M doesn't want to use it then I just think 'oh well'.

The idea that "AAC is hard work" was something that all of the parents who were interviewed talked about at length but contrasted this with comments such as using AAC "was worth the investment." One parent stated, "Well, it's not so much confidence but more motivated. Because you do see like the other kids that work with us and they do have good results and I do just want that for J but it's really hard." Another parent stated that:

Talking to the parents, what I found was that they all found it difficult and they all find it hard to use it and to find the time and do it right and we all have the same feelings. That it is really hard work and it is hard to get our kids motivated to use it.

Parents in the surveys did not make this comparison but one interviewee felt that their child who uses AAC had "a revitalised passion for using his Talker" following camp. This was a breakthrough as his mother reported that she had struggled to motivate her child to use the device consistently.

Inspiring. Many parents (n=8) commented that camp was inspiring in their post-camp survey and all three interviewees discussed this. One parent wrote "mind-changing experience" in her post-camp survey. Two of the parents used the word "mind-blowing" in their interviews and one used this word in their post-camp survey. One parent summarised the camp experience as "the whole thing [was] inspiring, profound and heartbreaking and uplifting" during her interview. All of the interviewees used variations of the phrase 'camp

was a real eye-opener' in that their perspective of what their child may be capable of and their educational and social possibilities. These comments are epitomised by the following quotes from the interviews: "We had no idea that there was such a range of different possibilities and how amazing that is" and "We were unaware of what people can achieve with AAC until we saw the role models talk to us. That left us speechless and was very inspiring."

Empowering. A sense of empowerment was expected based on the pre-camp surveys. However, only one parent wrote about this in her post-camp survey, saying, "I really had no expectations. However, now I feel more empowered as a parent." In contrast, all of the interviewees expressed feelings of empowerment gained from the camp experience. They discussed feeling empowered through meeting other AAC users and mentors; learning more about AAC implementation; being supported and encouraged by the staff; and feeling that everyone is 'in this together'. One parent talked about how she felt that her son was more empowered to use his AAC system to say things on his device that he would not otherwise be able to communicate, saying, "So, I think that has got to be really empowering for him and I think he gets that. It was mind-blowing!" and another parent talked about how her daughter felt more empowered to try things without her mum by saying "She was learning that she can do things with other people, not just with Mum." Two parents felt empowered to share their AAC knowledge at their workplaces and with friends, for example:

In my current job as an early childhood teacher to be able to advocate for things to get used for children who use communication systems at the kindy and also would be in a position of suggesting to SLTs that they refer to TalkLink.

All of the parents who were interviewed talked about how implementing AAC “is really hard work”. As previously stated, parents found it difficult to use AAC and find time to implement it. However, the comments about hard work were immediately contrasted by feelings of empowerment to keep going, exemplified by the quote “Its hard work but I can do it.”

Overwhelming. In contrast to the positive emotions described by parents in the post-camp surveys and interviews, parents also described feeling overwhelmed and at times confronted. Timing was the main factor that appeared to overwhelm parents, as reported in the surveys and for one mother in the interviews. Four parents commented that the tight scheduling within the timetable caused difficulties. These comments were explained in depth and recommendations were made, suggesting that the parents had been significantly impacted by this and had thought about it for some time. In the post-camp surveys, two parents reported that they struggled to balance the napping and fatigue needs of their young children (both children who use AAC and siblings) and their excitement to take part in all of the activities. Two parents reported struggling with the short amount of time allocated to meals and getting between activities as their child was PEG feed and had multiple and complex physical needs, seizures and pain. In the post-camp survey, one of the mothers wrote:

I was glad my son was here to help me. I didn't realise how difficult it would be at camp with J. It would have been difficult to get to things on time if I was dealing with her on my own.

The interviewee spent time discussing the lack of time between activities in her interview and that this caused some stress for their family, saying "It was too rushed ... we had to go and run to the next thing and for J that was all too much ... it was full on."

While timing was the main factor reported in the surveys, all of the parents in the interviews discussed feeling overwhelmed by the amount of information being presented and that the camp experience, in general, was quite overwhelming, for example, "We both felt really shell-shocked after that first day." Parents also commented on the intensity of connections between families and other camp attendees, which was both a positive and an overwhelming aspect of camp. One mother was surprised to not be with her child throughout the day, saying, "It was a little bit of a shock that the parents were separated for the children right from the start [for the morning sessions] like that but he had such tremendous support."

The three parents who were interviewed reported that they found the mentor presentations overwhelming. One "got really upset" comparing the mentor's transition to high school to her son's upcoming transition and feeling "really emotional" about how to support him with this. Another parent found the presentations overwhelming, as she had to confront her son's emergent communication and literacy skills compared to those of the mentor who was completing postgraduate university study. She said, "They [mentors] still

have a higher level of understanding things than J. And I always umm I always feel. How do you say it? We are always confronted by that... It is very hard” and “He doesn’t understand it. Well, not yet. I just think, if he ever does understand that, how communication, how powerful it is because his world is so small.” Combined with the feelings of rushing from one activity to the next, this parent felt that she did not have time to process these emotions until after camp.

Communication Outcomes. The parents perceived several positive communication outcomes as a result of attending camp. Parents reported an increase in some aspects of AAC use, increased confidence around using AAC for the whole family, increased knowledge around general and specific aspects of AAC and increased expectations of themselves and others related to the frequency of AAC use.

Increased AAC use. One important finding was that some parents reported that their child increased their use of AAC, in term of frequency of use and number of words per phrase, during and after camp. For instance, one mother reported that “She is asking to use it [PODD]” which was a new request and another mother recounted that she “learnt that my boy is a rock star Talkie user and... we couldn’t get him to turn his Talkie off at mealtimes.” The results of the post-camp survey question “My child improved his/her ability to maintain a conversation using his/her communication device” where that most parents (n=9) were ‘neutral’ but five ‘agreed’ and one ‘strongly agreed’ indicated that although some children may have increased their AAC skills, many still needed support to learn to use their communication device. One parent pointed out that 5 days is a short period for children

with CCN to gain skills or change and said, “We feel we've taken big strides towards that in these 3 days. While it is hard to assess improvements in A's ability to use TouchChat, no doubt we as a family have gained hugely from this experience.”

In the interviews, two parents reported that their children started to use their AAC system more, regarding mean length of utterance and frequency of use, during and after camp. One mother said, “M is using his device every day and... more often than not, it is something that I wouldn't have been able to understand if he hadn't used his device to tell me” and that “He is using whole sentences now rather than just using single words.” The interviewee who did not see an increase in her son's AAC use did, however, say that the family now “use it every day now [for ALS]”, as did the other parents.

Increased confidence. Several questions in the post-camp survey and interview questions related to confidence associated with AAC. The pre-camp surveys did not ask about the parents' perceptions of their child's confidence in using AAC, however in the post-camp surveys an equal number (n=5) of parents 'agreed' and were 'neutral' about whether their “child's confidence in using his/her communication device improved”, while 4 'strongly agreed' and only one 'disagreed'. When it came to the question of whether their “child gained more confidence in initiating communication using his/her communication device” most (n=6) 'agreed' with this statement and three 'strongly agreed' while five felt 'neutral' and one 'disagreed. In the open-ended responses, five parents reported feeling that their child had become more confident using their AAC system.

The family as a whole appeared to have gained confidence specifically in AAC implementation according to the data from the interviews and post-camp surveys. In the pre-camp surveys, there was a range of feelings towards parent's confidence and the confidence of their child who uses AAC. Most of the parents 'agreed' (n=8) with the statement "I feel confident in using my child's communication system", however, four parents disagreed with this statement, three felt neutral and one 'strongly agreed'. This outcome changed significantly at the time of the post-camp survey where almost all of the parents either 'strongly agreed' (n=6) or 'agreed' (n=6) and only three parents felt 'neutral'.

In the pre-camp surveys, parents mostly felt 'neutral' (n=6) about their confidence "in creating communication opportunities", while the rest were evenly split between 'agreeing' (n=5) and 'disagreeing' (n=5). Parents were almost evenly spread between 'agreeing' (n=6), feeling 'neutral' (n=4) and disagreeing' (n=5) about their confidence "in prompting my child to use their communication device" in the pre-camp surveys. These questions about creating communication opportunities and prompting were not asked again in the post-camp survey but parents reported a general increase in their confidence regarding AAC abilities in the open-ended post-camp surveys. Several parents (n=6) stated that they felt more confident. For example, one parent wrote, "We have become more confident using B's PODD with her and trying new times to use it" and another parent wrote, "Vastly increased confidence in using the TouchChat app and strategies for using it 'consistently' in everyday life and situations."

Increased knowledge. All of the parents in the interviews and many in the post-camp surveys stated that they had learnt a lot during camp despite the short duration. Four distinct aspects of increased knowledge were evident in the data. Parents discussed their general increased awareness of AAC, increased technical skills and increased understanding of ALS in both the post-camp surveys and the interviews. A few parents also discussed increased sibling knowledge of AAC and being a good communication partner in the post-camp surveys.

General awareness of AAC. There appeared to be a general increase in AAC awareness and knowledge following camp. This is made apparent by the positive responses to the post-camp survey question “I feel the camp experience provided me with tools to help my child become a better communicator” where most parents (n=8) ‘agreed’ and almost all of the rest (n=6) ‘strongly agreed’ with this statement. The morning parent workshops appeared to be one of the factors that resulted in increased knowledge. Eight parents commented positively on the workshops in the post-camp surveys, with one parent saying “The camp covers a broad range of topics associated with AAC, which helps me crystallise what we need to do to move forward” and another writing “All of the seminars were fantastic! Really interesting and informative.” This was reinforced by post-camp survey data where half of the parents (n=8) ‘strongly agreed’ that “the parent workshops in the morning were useful and I gained knowledge and confidence because of them” and no one ‘disagreed’ or ‘strongly disagreed’. However, five parents reported feeling disappointed by the training as they “didn’t really learn as much as I hoped” because “most of what was covered I had heard before but it was good to be reminded anyway”. Some of these parents

also reported that they did not want to spend much time discussing their feelings or support needs as they had already covered these topics as part of their disability support groups.

In the interviews, one parent commented on learning more about multimodal communication and she emphasised that this learning was important for her family. She stated that, before camp, she had thought AAC was a hierarchy rather than a continuum and did not realise that low tech communication could be just as effective, if not more effective, in the right situation as high tech forms of AAC. This learning is exemplified by the following quotes:

The main thing I learnt more about was the core boards. I guess that in the past I had seen them more as a level thing. At first you do this and then you abandon it because you are using your Talker. Like it's a progression or something.

Later she also said:

I can now see that, well it kind of revived my idea of being like they are just alternatives of the same thing that you can use any time and you can actually use them both and at different contexts, they are both useful. It might just be me thinking that we 'graduate' from a core board to a Talker.

In general, parents reported positive perceptions of the training provided, however, some recommendations were provided for future camps. Several parents (n=6) mentioned that they would have liked to observe therapists working with their child who uses AAC to gain ideas around implementing AAC and others asked for formal 1:1 sessions with a therapist to move to the "next milestone". One parent requested a general workshop, saying, there was

a need for “‘Communication 101’ for engineers, farmers, non-educational professionals and other dummies like me”.

Technical skills. Camp appeared to have met most parents’ expectations around learning technical skills but some were left unmet. Learning technical skills was frequently commented on in the pre-and post-camp data. In the pre-camp survey most (n=6) ‘agreed’ or were ‘neutral’ with feeling “confident in programming/editing my child’s communication device” although two parents did not answer this question and one ‘strongly disagreed’, showing the range of perceptions within the group. Learning technical skills was one of the topics highlighted by a majority (n=10) of the parents in the pre-camp surveys although there was a range in needs from beginners to advanced technical training required. Six of the parents wrote about how they had “learned some editing that is going to help a lot” and other specific technical training needs. Nevertheless, three parents were disappointed with the lack of technical training they received and felt that the “care and share session on Saturday morning” did not meet their needs, as there was too little time for editing. Some parents wanted more technical training as expressed by two parents who said, “ I was hoping to learn a little more on editing/improving what is currently on her device to help her communicate better” and “More editing instructions and hand on advice about the device.”

The three parents who were interviewed, all reported increasing their technical skills, such as programming, using visual scenes and problem-solving, although one parent wanted to learn even more and reported that she required follow up support after camp. The parents

likely learned these skills through the parent programme but also through immersion and from spending time with the mentors. However, this was not specifically asked during the interviews.

In the interviews, one mother felt that it was important that the whole family attend camp so that the AAC 'load', particularly around technical support, was more evenly spread across each family member. She felt that, previous to camp, M's dad was not as supportive of AAC implementation and couldn't help with the technical side of using the AAC device because he was not able to attend training due to work commitments. Therefore, having a holistic camp, where all of the family members were able to attend reduced the 'burden' and empowered everyone in the family. This mother expressed that:

I have a lot more ability to guide him [child who uses AAC] as well as myself ... and I feel like I know heaps heaps more about navigation and some really specific skills about loading things on to it and dealing with difficulties.

She followed on to say:

I think that if at all possible... if both parents can attend ... because [dad] really needed to see how capable M is. Because I think that one of the things that we have really, well, we have argued about over the years, is that R is not supporting me in this. And that. And he doesn't know how to work it but when he saw what was going on at KiwiChat Camp, it was worth the investment.

Aided language stimulation. Parents used the term modelling, rather than ALS when discussing their learning about this strategy. In the pre-camp surveys, five parents

mentioned modelling as something they wanted to learn about so that, for example, “we can help M progress his usage and subsequent ability to communicate better.” There were a range of negative responses to the question “I feel confident with modelling language on my child’s communication device” in the pre-camp surveys, with most parents ‘agreeing’ but five parents ‘disagreeing’ and one ‘strongly disagreeing’. ALS knowledge increased by the end of camp for several parents (n=6) who mentioned learning more about ALS through the parent workshops and AAC immersion. One mother remarked, in her post-camp survey, that they were reminded of the value of modelling by saying, “Being at camp and seeing lots of modelling with communication devices and lots of core boards being used regularly helped him and us remember how valuable that modelling is.” Another mentioned using the core board for ALS in a range of environments such as using them “more at home and for Sunday School.”

All of the parents who were interviewed learnt more about ALS and were motivated to continue to use ALS when they returned home. One interviewee reported that since camp “I really took on board about modelling using the device so I will say 'let’s see if we can find this together' 'what pathway will we need to take to get that word'.” They discussed the importance of being immersed in ALS and how quickly this allowed their children to gain AAC skills, for example:

I think it was good for me to see how good it is to do it little and often. I know the best thing to do is to use it all the time, which I still don’t but it was really clear how quickly she gained skills by being immersed.

One mother likened camp to an immersion school by saying “It was like going to a Māori immersion weekend... the whole atmosphere of using the devices all the time and that there are so many different ways of communicating” and how this consistent, enthusiastic use of AAC motivated and inspired their family.

Sibling knowledge. An increase in sibling AAC knowledge was only mentioned as an expectation by two parents in the pre-camp surveys, with one parent saying she hoped for “Perhaps some session where siblings are modelled/shown how to use AAC to model for their special needs siblings.” However, 10 parents commented on this in their post-camp survey. They stated that some of the siblings appeared to learn some specific skills such as “if you don’t know something write it down” to observing their general “enjoy[ment of] meeting other children that used AAC” and learning “How to communicate with her sister more and enjoyed seeing how others use their AAC.” In the post-camp surveys, two parents suggested that the siblings should have their own training programme, like the parent workshops, as children who use AAC can sometimes “idolise” and “copy” their sibling, which would be useful if the sibling was able to model on the AAC system. Sibling training was not mentioned by any of the interviewees but one child did not have siblings and another’s sibling did not attend camp.

Increased expectations. Increased expectations around frequency and competency of AAC use were seen in the post-camp data. Fourteen comments were made about increased expectations in the post-camp surveys. The comments ranged from increased expectations of the child who uses AAC to increased expectations of the parents themselves

and their level of support for their child. They expected more from the school teams and for the AAC system to be used for a greater variety of language functions, “not just for food, drink and toys.” A few parents (n=3) had written down their goals for when they got home, for example, “To find five situations where we can consistently use/model the use of A's iPad for communicating simple sentences.”

In the interviews, parents reported that their expectations around AAC implementation increased after attending camp. All of the parents stated that their beliefs about what their child was capable of achieving socially and academically through learning to use their AAC system increased while at camp. One parent said, “It all comes down to what you believe a child may be capable of” about how much effort the team puts into teaching the child who uses AAC. Parents’ expectations of themselves also increased. This is illustrated by the quote “And it's not about a whole lot of time but it is just about an expectation.” Their expectations of family and friends increased, demonstrated by the story, as well as their expectation of school teams:

The very first things that we did when we left KiwiChat Camp was go and visit friends in Rotorua and we said to them, we are expecting M to use this, so we would like you to say 'M I can't understand you. Could you please tell me on your device?' So, we expect that wherever we go and we have hooked up with other families and friends and we have still said this is our expectation.

One parent commented, “It’s not even about the children, it is about the adult's expectation.” These parents inferred that these increased expectations resulted in the need for follow up at home and school to continue learning and to ‘get others on board’.

Parents identified a range of communication and sociocultural outcomes from camp, which increased their expectations around AAC implementation. However, all of the interviewees discussed their concerns about the challenges of getting everyone else (extended family, school staff, caregivers, etc.) on board with AAC implementation. All of the parents, who were interviewed, discussed the challenge of getting the school team on board. For example, one interviewee said, “She has a really motivated teacher at the moment but the problem is that teachers are just so busy and so it is really really hard to do AAC” and later said “but it is hard to get to the next layer of people, which is school and her dad's family and that is the sticking point.” Another interviewee stated that she needed follow-up support at home and school after camp finished and that this should be considered for the next camp. Parents need support to share their increased expectations and provide the teams with training to implement these.

Sociocultural Outcomes. Several sociocultural outcomes were discussed during the interviews and written about in the surveys. The following outcomes will be discussed in the subsequent sections. Parents enjoyed camp. They connected with other families of children who use AAC, with mentors who use AAC and with staff. Parents felt a sense of belonging and one parent discussed how her daughter’s sense of identity developed during camp.

Enjoyment. Many of the parents (n=7) expected to “have fun with my family” or to enjoy “a family holiday” in the pre-camp surveys. The parents’ expectations were mainly met as demonstrated by the Likert and open-ended question responses in the post-camp

survey. Most of the parents 'strongly agreed' (n=5) or 'agreed' (n=5) that camp had met their expectations. Only one parent reported that they disagreed that camp met their expectations and four felt neutral about this. Most of the parents (n=8) felt 'strongly' satisfied with the camp experience, while one felt neutral about this and the rest 'agreed'. One parent commented that "This was our first camp... I feel any expectations may have been exceeded by the experience. Camp was very good." In addition, another parent reported in the post-camp survey "If I'm honest I did not have high expectations" but prefaced this with the ways that camp had exceeded her expectations. There was a very small range of answers about whether parents felt that the camp experience was helpful with the answers being either 'strongly agree' (n=7) or 'agree' (n=8). Two of the parents felt that camp was so beneficial that they explicitly asked for camps to be held more frequently saying that they would like "camp to be held annually [rather than biannually]" and "more of them (I wish!!)."

Parents enjoyed camp, as evidenced by the positive responses to questions, such as "my child enjoyed the camp experience" where all of the parents answered either 'strongly agree' (n=9) or 'agree' (n=6) and "I would send my child to this camp in the future, if I had the opportunity" where even more parents 'strongly agreed' (n=11). Most of the parents (n=10) 'strongly agreed' that they "would recommend KiwiChat Camp to a friend whose child uses AAC" and the rest 'agreed'. Eleven parents commented that they enjoyed camp in their post-camp surveys for a range of reasons, such as camp provided "lots of laughter, dancing and fun catching burglars" and that "The entire experience was invaluable. The whole thing was so well thought out and significant in every aspect." The parents either

'strongly agreed' (n=10) or 'agreed' (n=5) that their "children were safe at camp" and most of the parents 'agreed' (n=10) that "the camp activities were appropriate for my child" and this contributed to the positive perceptions and enjoyment of camp.

All of the parents who were interviewed also expressed feelings of happiness or pleasure about attending camp. They said it was 'fun', 'awesome', 'fantastic', 'luxury' and 'cool'. They all expressed that "We would love to go every year" and each said something similar to "I think that the kids that haven't had that opportunity yet are really missing out and that their families are really missing out." The camp activities and interpersonal connections were enjoyed and one parent said that "Even though she was doing work every day it wasn't like [working] ... But this the camp experience felt like she was just having this awesome fun experience not like she was not so much of a demand." Camp was recommended by all of the parents.

Although most parents enjoyed camp, several suggestions were made to improve future camps. Some related to the facilities or activities, which the camp planners had no control over but this was fed back to the camp managers. Two parents commented that the accessible facilities were important and resulted in a "fantastic" and "great" experience. One parent requested a hoist into the pool. Several parents (n=4) commented on the food. Some parents reported that the food was "excellent" or "awesome" and additionally requested that more 'kid friendly/fussy eater' food be available or food that caters to various religious requirements. Several (n=5) parents requested longer meal times as their children were slow eaters or they had multiple children to manage during meal times.

Having a range of food choices that cater to all dietary needs (e.g. fussy eaters, religious and allergy/intolerance needs), appears to be an important aspect of enjoyment of camp. There was only one comment reminding the researcher about the necessity of age appropriateness of activities for children who use AAC and the need to ensure they are motivating for children with a range of special interests.

Connections. Expected and unexpected connections were made at camp. Before camp, most parents (n=7) 'disagreed' about feeling "connected to other families of children who use AAC devices" in the pre-camp survey. All of the parents who were interviewed had met others who use AAC before coming to camp. For instance, two parents said they had "met other [AAC] users when we've attended KiwiChat Days", and two parents said that they had "met the students at [special] school but not the parents." However, these parents reported that these interactions did not result in social relationships built on a shared common experience and did not impact the families much. For example, one parent said:

We have met other users when we've attended KiwiChat Days but this was a personal first for both of us to be able to hold a conversation with somebody who was using a device for communicating. The KiwiChat Days have never been quite the same for us in the sense that we have not been able to view proficient users. Just lots of people who are at the emergent levels.

Camp, in contrast, resulted in deep, albeit short-lived connections with children who use AAC, other families, mentors and staff.

Children who use AAC. The interviewees did not specifically reference the benefit of their child who uses AAC connecting with others who use AAC. However, they did mention that their child had “made friends” or “saw everybody using AAC and that was the huge benefit” and “interact[ed] closely with other kids with disability.” The connections the children made was framed positively.

Families. Ten parents stated that connecting with other families was useful on their post-camp survey. Nine ‘strongly agreed’ and six ‘agreed’ that “Networking with other families who have a child who uses a communication device was useful.” Most (n=9) parents ‘agreed’ to feeling “more connected with other families (compared to before I came to KiwiChat Camp) and will continue these connections” although one disagreed. As this question actually contained two parts, it difficult to know whether they ‘disagreed’ with feeling more connected or continuing the connections.

All of the parents who were interviewed, enjoyed connecting with other families, for instance, one parent said:

We just feel that it was so great meeting all the other kids. It was awesome because they are all so different in terms of complexity and severity and stuff but we all just has this one thing in common.

They sometimes connected with families who had children with similar diagnoses, as seen in “I guess we connected more with families with children who had cerebral palsy.” These connections were deeply felt at camp. However, there was no indication from the interview data that they continued after camp. A quote that demonstrates this is “There wasn’t

anyone who we made personal connections with [after camp] but there might have been others who live closer together who did.” This quote as well as the following quote “It was good having someone attend camp who was close to our area” illustrates that the geographical proximity that separates families caused some issues with the continuation of connections. One interviewee stated that they were able to meet up with another family from their city but one of the families who lives rurally did not know any other AAC users within an hour’s drive of their home. Despite the physical barrier of continuing these connections “KiwiChat Camp format [was] incredibly powerful” and “was great because it makes you realise that you are not the only one with such complex needs.”

Mentors. Connecting with the mentors was an unexpectedly positive experience at camp. Most parents ‘disagreed’ (n=5) or ‘strongly disagreed’ (n=5) to “interacting with older children or adults who use communication devices” in the pre-camp survey but most ‘agreed’ (n=7) or ‘strongly agreed’ (n=6) that “Interacting with the AAC Mentors was useful and I gained knowledge from them” in the post-camp survey. Several parents (n=5) commented that connecting with the mentors was a positive aspect of camp in their post-camp surveys. One parent said that she loved listening “to the perspective of the older students who share their triumphs and trials in using AAC in education. Got lots of handy hints.”

The interviewees indicated that they had various emotional responses to meeting the mentors (as reported in the emotional response theme) and also increased expectations around AAC implementation. For one parent, meeting the mentors was “a personal first for

both of us to be able to hold a conversation with somebody who was using a device for communicating.” Having the mentors attend the whole camp meant that they could teach families through immersion about AAC implementation and allow families to imagine how their expectations could increase. One example of this is “She taught me how to do that. So again, another experience of being in an everyday experience of someone who is using a device to communicate and how fantastic that was for me”, while another example is “The power those girls have to be able to use it like personally was just amazing. I was just blown away by them. And it was a real eye-opener.” Connection with the mentors also “had a really positive impact and I know [mentor] and [mentor] in particular spent some time with M.” This shows how having older, experienced individuals who use AAC interact with younger, less experienced children who use AAC, can change their own beliefs and motivation about what they could achieve.

Staff. Parents also experienced positive connections with the staff who supported them through the camp experience. Over half (n=9) of the parents thanked the TalkLink staff in their post-camp surveys and wrote “All the staff and volunteers and students were just so genuinely helpful and patient. It really made the weekend run well having so many of them about/available” and that the staff were “passionate”, “caring” and “knew what they were doing”. One parent stated in her interview “There was an absolutely commitment from all present. Your belief in our children has really helped” and another parent commented on “how skilled all the TalkLink staff are at using all the systems” and that this helped in the learning process. The Likert data also supported the thought that the

“trainers/therapists was skilled in facilitating group discussion” with most ‘agreeing’ (n=7) and most of the rest (n=6) ‘strongly agreeing’ with this statement.

Sense of belonging. Feeling a sense of belonging was an unexpected perception of camp. One of the barriers that was mentioned several times by all of the parents in the interviews was that implementing AAC is hard work, for example, parents commented “having the device is tricky” and “it is really really hard to do AAC”, however, this was contrasted with the sense of all of the families being in the same position. For example, one parent said, “You could see that others had the same struggles and we are all in the same boat and we are all trying and basically you are not alone.” Another commented that even though the connections may not continue after camp the sense of togetherness was still meaningful. For example, she said, “The other aspect of networking was there was a sense of ‘we are all in this together’ even though we were with each other for a really minute period of time of our whole lives”, while another parent said, “It was for that period of time you actually care about that person’s kid and they care about your kid and you want the best for everyone.” This sense of closeness also resulted in one parent saying that they “felt really like we fit in at KiwiChat Camp. We don’t usually meet people with such complex communication needs so it was great.” Similar comments were made many parents (n=12) in the open-ended questions of the post-camp survey, where one parent commented that they had “a sense of ‘fitting in’ with a group of people in a way that our family generally doesn’t back in the ‘real world’.” Another parent also commented that “we are not alone in the struggles of having a child with a disability” and one parent represented others’ views when she discussed “normalising use of the AAC device” at camp.

Developed identity. Only one parent talked in her interview about her child developing her sense of identity at camp. However, she placed significant emphasis on this and spoke about it at length, saying, “You could see that she was getting a bigger sense of her place in the world” after meeting the mentors and other children who use AAC. Identity was not one of the topics in the interview but when asked, “Is there anything else you want to talk about?” she talked about how they ‘fit in’ at camp and that:

She is too little to see them [mentors] in a positive or a negative light but she just sees them as big stars and if she sees someone in a wheelchair and thinks they are great and I hope that she always feels like that.

Findings - Children who use AAC

The results of the post-camp survey of 13 children who use AAC are presented in Table 6. It was not appropriate to apply statistics to this data set as there is a very small range from agree to disagree and in all questions, the mode and median would be the same: agree.

Overall, the responses indicated positive perceptions towards a range of camp activities and experiences. All of the children who used AAC enjoyed camp and most (n=9) would return if they have the opportunity, although two did not answer this question and one indicated that they did not want to return. Most of the children reported learning more about their communication system (n=8) and also indicated that they wanted to use it more when they left camp (n=12). All of the children bar one reported that they used their communication

Table 6

Post-camp Survey Results of Children who use AAC

	Question	Response		
		Disagree	I'm not sure	Agree
1	KiwiChat Camp was fun			13
2	The camp activities were interesting	3	2	8
3	I enjoyed the camp show		2	11
4	I learnt a lot about using my communication device at KiwiChat Camp		5	8
5	I used my communication device to talk to a lot of different people at KiwiChat Camp	1		12
6	I want to use my communication device when I get home	1	3	9
7	I made friends at KiwiChat Camp ^a	1		10
8	I want to go to KiwiChat Camp again if I have the chance ^b	1		9
9	I would tell my friends about KiwiChat Camp ^a	1	1	9
10	Anything else you would like to tell us			<p>My favourite thing was catching Smelly Sid and Billy Black [characters who performed each day].</p> <p>My favourite thing was dancing in the disco.</p> <p>No more camp activities because I was tired. Because I wanted to do stuff with the sibling programme, with my brother.</p> <p>I enjoyed the camp show with mum and dad. The helpers were really good.</p> <p>No.</p> <p>Yummy food.</p> <p>Yes. That's sad. [sad because it's time to go home – written by mum]</p>

Note. ^aTwo children who use AAC did not answer this question. ^bThree children who use

AAC did not answer this question

device to talk to many different people at camp and almost all (n=10) reported making friends during camp. Seven children filled in the 'anything else you want to tell us' section, sharing a range of comments. Most of these comments were positive perceptions of the camp activities or food and one reported feeling sad to be leaving camp. One child reported feelings of separation from their sibling and the fun activities their sibling was engaged in during the morning activities. The last three questions on the survey were not answered by two of the children, which may be due to time limits (they did not get to the last page) or an error when filling in the survey (they did not see that there was one more page).

The SLT students were asked to document how the children completed the survey and how much support they required. Two of the children independently completed the survey and four children used partner assisted scanning. Three children required verbal prompting and visuals and two required physical prompts. One child who used AAC used a mixture of independent pointing and hand over hand prompts from his mother. One required a forced choice alternative for question 10, as they did not have the vocabulary required to answer this in their AAC system.

Findings - Sibling

The siblings were interviewed in two groups and their results were analysed as per the GIA method. Two global themes emerged from the data along with several organizing themes: Enjoyment (of camp in general, of activities, of connecting with others use AAC, of connecting with mentors) and outcomes (increased knowledge of AAC systems, increased knowledge of how to be a good communication partner, increased motivation to learn,

increased confidence, increased AAC use). These themes are presented in Figure 2. The global themes, organising themes, definitions and examples are presented in Appendix M.

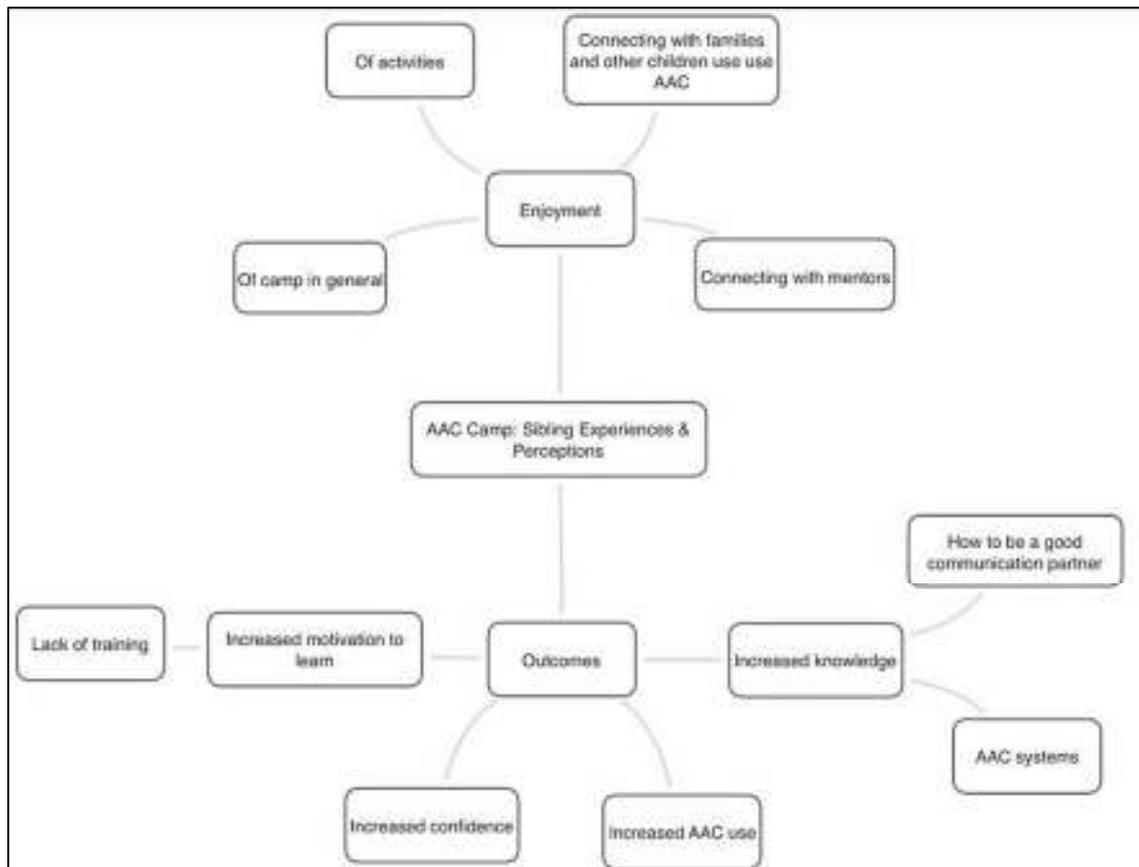


Figure 2: The experiences and perceptions of siblings of children with complex communication needs about attending KiwiChat Camp: Themes

Enjoyment. Enjoyment was a global theme that was discussed by the majority of the siblings around a range of camp aspects and encompassed four organising themes. All of the siblings commented on their enjoyment of camp and all of them said “yes” when asked, “if you had the chance would you like to come back to camp again.”

Camp in general. All of the siblings expressed feelings of enjoyment regarding attending camp. They used phrases such as “I loved it”, “It was really cool” and “It was really fun” to describe their general camp experience. Each of the following organising themes (enjoyment of activities, connecting with others who use AAC and connecting with the mentors) appeared to contribute to the overall feeling of enjoyment expressed about attending camp.

Activities. All of the siblings indicated that there were activities that they enjoyed and most indicated that there was nothing they would change about camp. Two siblings, however, mentioned some activities they would not choose to do again, for example, “I didn’t really like writing in the book every day. Recording what I did for the day” and “The boring thing about this was human foosball.” One mentioned enjoyment of the flying fox but then also stated, “I just don’t like that you had to pick it up and walk all the way back. It takes all your energy and fun from the flying fox bit and when you walk it is just yuck”. Therefore, some parts of a single activity were enjoyed and others were not.

Connecting with others who use AAC. Many of the siblings indicated that they enjoyed meeting people who use AAC systems. For example, one sibling said, “It’s just cool meeting other people who are learning the same things that you are.” One sibling commented that he had not “chatted with other kids who use communication systems at camp” because “there hasn’t been much time to do it” but that this is something he would have liked to do. He mentioned that he had time to “talk with the parents and stuff during eating time but the kids don’t normally have their communication devices with them then”

but that he would recommend “time to mingle with people” and for “the kids [to bring] their communication devices to meal times” for future camps. There was a sense of bonding over a common understanding between most of the siblings. The enjoyment of these connections appeared to allow new information about CCN and AAC to be gained, for example, one sibling said, “I liked actually sort of like when we weren't doing the activities like how the different siblings communicated with each other. That was cool to sort of see the different ways that people have been enabled to do that.”

Connecting with mentors. Several of the siblings stated that they had not met individuals who use AAC, other than their sibling, before coming to camp. For example, one sibling said “My brother. He uses a communication device. No one else” and another said, “No, I haven't met anyone.” While two brothers reported that their “sister goes to special school, so there are quite a few kids who use different devices or ways of talking. So, I've seen quite a few different things.” The children shared positive comments about meeting the mentors at camp. One sibling shared how excited he was to have connected with one of the mentors that he bought him a present: “It was awesome! Actually, I bought the mentor something from the camp shop.”

These connections opened the siblings to new ideas about access methods, for example, one sibling commented that meeting a mentor was “Cool! Because it was cool that she can use her Talker with her big toe.” These connections also provided perspective on the AAC learning journey, for example:

They are quite a lot better at using it because they have had more use of it and it is just like like if we learnt a new language but it's like their first language for them though. So, it's just like really fluent and easy for them to use it and like when you see like they are learning it because it is quite hard and they get confused about it. Yeah. It was quite cool.

This quote demonstrates that he understood that learning to use an AAC system is like learning a new language and this takes time and effort for the person using AAC.

Only one of the siblings said that he had “not really” interacted with the mentors much. This sibling also mentioned that he was motivated for his sister and mother to attend camp again but that he did not feel that he had gained much from it. He had been required to put in much effort to help his mother look after his sister, so he had not had as much time to meet others and enjoy the activities. When asked why he sounded hesitant, he said:

No. It's just that it is the same. It would be another chance for my sister to learn more about using the device and she would probably she would be a bit older and would probably be able to use it a bit more by then.

He followed on to say “Umm. I wouldn't mind coming back” but then shrugged his shoulders and looked indifferent.

Outcomes. Four organising themes were identified within the global theme of outcomes: increased AAC use, increased confidence, increased motivation to learn about AAC, and increased knowledge. The organising theme of increased knowledge was made up

to two codes: increased knowledge of AAC systems and increased knowledge of how to be a good communication partner.

Increased AAC use. Two siblings commented on their siblings' increased use of AAC since being at camp. Increased AAC use was not asked about directly but the discussion surrounding the sibling's comment that "my brother has been using it to communicate a lot more ... since being at camp" emphasised how proud and excited he was about this outcome. Another sibling said, "She kinda knows how to use it a lot more, so you can understand her more." Camp is a short period of time, so for this outcome to be noticed by two siblings is significant as most of the other siblings made comments about it taking time to learn to use AAC, for example:

It was quite new to us to start off with it but I think my sister might start using it a bit more seeing that other people will do it. We are going to try to push her to use it as much as possible.

Increased confidence. When asked about whether camp has made them more confident using AAC, all bar one of the siblings responded 'yes'. An example of this is "I think I am a bit more confident in using it. I think I know a bit more than when I came here." One sibling felt that he had 'about the same' level of confidence as before camp.

The siblings reported increased confidence around a range of different AAC related tasks, including knowing where words are located, using the system with their sibling and using the device to support receptive language. For instance, one sibling said, "that we can speak

to them more.” One sibling stated that he did feel more confident but that he was “not really sure where the words are” and that he would like more training to increase his confidence around this. This increase in confidence demonstrates that intense but brief AAC immersion over a very short period may be effective in supporting siblings AAC learning needs.

Motivated to learn more about AAC. All of the siblings demonstrated motivation to learn more about using AAC during and after camp. During the interview, it was apparent that the siblings had received limited training about AAC in general and their sibling’s AAC system in particular. One sibling said “I know half about communication devices but not a lot” and another said, “Yeah, a little bit. Like when we get different ones sent home from school, we get shown how to use them” however, while saying this he shrugged. One sibling commented that he had not participated in any training at home, saying “Not really. Not really. Na” and then explained that observing others to try and figure out how to use the AAC system is “ok” and that:

Umm. I guess it has its upsides and downsides as well. Because it’s sort of I guess will give my sister a way to learn to use it herself and sort of use it for different things but I mean having another way to - another side to do it - sort of having it - I mean we communicate with other people who are using it. So yeah.

This quote demonstrates the internal struggle he was verbalising between having someone show the whole family how to use AAC effectively and having to figure it out yourself which slows you down and might help the sibling who uses AAC to problem solve on their own.

The lack of training and motivation to learn more was highlighted by the length of time that was spent discussing this topic compared to others. It was also emphasised by the increased emotional response to the topic. When asked whether they had ever had training on AAC, most of the siblings looked down, dropped their eyes, and shook their heads sadly. In contrast when asked about participating in training after the interview was concluded they all, bar one, said 'yes' and smiled and nodded their heads enthusiastically.

After discussing the lack of training the siblings had been provided with, they were asked if they would like to participate in a half hour training session about using communication devices. All but one of the siblings reported that they would like to participate in training on how to use their sibling's AAC system at camp in the next session. The one sibling who did not say "yes" to training indicated that "if the rest of the group is going to do training" then they would. Their enthusiasm, demonstrated that the siblings were motivated to learn and were willing to sacrifice their time, which could have been spent participating in camp activities, learning about their sibling's AAC system.

Increased knowledge. As has been explained, the organising theme of increased knowledge was made up to two codes: increased knowledge about AAC and increased knowledge of how to be a good communication partner. Several of the siblings (n=4) mentioned that they had learnt a lot about the variety of AAC system. They had learnt that there are many different access methods for AAC systems at camp, for example, one said "You can use your eyes" and another said, "Well if they can't use one part of their body, they can use another part." Three siblings mentioned that they had learnt more about the

navigation pathways of their sibling's AAC system, for example, "I've learnt lots of new pathways on the TouchChat. Well, I've learnt where the keyboard is if I can't find a word." There also appeared to be a general increase in the understanding of multimodal communication and that AAC is just another method of communicating a message. This is highlighted in the quote "like if you don't know how to talk you can like use like push whatever button you want so that you can tell what you want or what to say." Three of the siblings said that they "haven't really learnt anything new" but that they were more motivated to use the AAC system in conversations.

The siblings were not explicitly taught strategies around how to be a good communication partner at camp. Despite this, a few siblings mentioned learning some strategies while being immersed in AAC during camp. Two brothers discussed how "I think my sister might start using it a bit more seeing that other people will do it. We are going to try to push her to use it as much as possible" because he and his family had learnt a bit about ALS during camp. The other brother said "Well my sister like it was kinda new so I've learnt how to use it and kinda communicate with her" but then struggled to communicate exactly what he had learnt, saying "Umm. Like like I don't really know. Yeah." These brothers were the ones who had talked about knowing a 'little bit' about AAC through observation but being highly motivated to participate in explicit training. Another sibling said that he had learnt about using the AAC system throughout the day rather than for a dedicated 'communication time' and this is shown by his quote "I guess sort of just using it in conversations. So like if she had a good day at school and stuff like that." One sibling, however, was honest about their lack of AAC use at home saying, "I don't think I learnt much about it but just use it more because

we don't use it much at home. She has got different things that she does that we know what she means but other people probably don't" and then indicated that he was keen to participate in training so that he could show his sister how to talk to people who don't understand her.

Conclusion

In conclusion, most expectations were met and parents had positive perceptions towards the camp experience. Children who use AAC and siblings enjoyed camp and benefited from the camp experience for a range of reasons. Families responded to camp with multiple interconnected emotions and there were positive sociocultural and communication outcomes for the children who use AAC, their siblings and parents.

Chapter Five: Discussion

The purpose of this study was to investigate the perceptions and experiences of families who attended KiwiChat Camp 2016, a camp for children with CCN who use AAC. Through the use of multiple methods (surveys, interviews, focus groups) and multiple informants (parents, children who use AAC, and siblings) information was gathered and analysed. The pre-camp expectations of parents towards camp and AAC were documented, and then the post-camp perceptions and experiences of parents, children who use AAC and siblings were analysed. In this chapter, the participants of KiwiChat Camp will be discussed. Then the results will be discussed with reference to existing literature. This discussion will centre around four key themes: enjoyment, emotional impact, communication outcomes and sociocultural outcomes.

Participants

This study aimed to provide more comprehensive descriptions of the camp attendees compared to previous studies to increase the transferability of the findings. Only one previous study (Myers, 2007) provided an adequate description of participants. The results from this study indicated that children with a variety of diagnoses and who use a range of AAC systems might benefit from attending camp. This study also showed that families from a range of cultures and geographical areas around New Zealand might benefit.

Enjoyment

‘Expectation is the root of all heartache’ is the modern translation of one of Shakespeare’s quotes from *All’s Well that Ends Well* (Shakespeare, 1623). In this case, expectations that camp would be fun and result in positive experiences and outcomes for the whole family were met and heartache was not caused. The following results indicated that a number of factors contributed to the enjoyment of camp: age appropriate and highly motivating activities for all family members; connecting with other families, staff and mentors; support from enthusiastic and competent staff and volunteers; accessible facilities; good food that catered to a range of dietary needs; and finally, observing increases in communication outcomes over the progression of camp. Some parents reported that the fun activities and enthusiastic attitudes of everyone at camp meant that learning did not feel like a chore. Findings from other studies also indicate that camp is an enjoyable time where learning AAC is fun for the child who uses AAC, as well as parents and other attendees (Berger & Feucht, 2012; Bruno & Dribbon, 1998; Bruno & Trembath, 2006; Dodd & Hagge, 2014; Kent-Walsh et al., 2010; Mbangamoh et al., 2008; Myers, 2007).

Emotional Impact

The emotional impact of camp was significant. Previous studies did not highlight the emotional impact of camp on families. They focused more on the communication outcomes rather than capturing the broader camp experience. Berger and Feucht (2012) were the only authors who included quotes about the emotional impact of camp, for example, “Megan’s mother, with tears in her eyes, says, “Thank you so much for starting this camp. It means a lot for all of us.”” (Berger and Feucht, 2012, p. 82). In the current study, all of the parents

who were interviewed and many of the parents who were surveyed discussed the emotional impact of camp and described it as being overwhelming but inspiring, motivating and empowering. Many of the parents, like those in the study by Berger and Feucht (2012), also expressed thanks to the staff who supported them through camp.

The results of this study highlighted the overwhelming nature of camp for parents. The children who use AAC and their siblings did not comment on this during their surveys or interviews, therefore at this stage, it is not possible to draw conclusions for the whole family. The parents' feelings appeared to arise from the intensity of connections made during camp, as well as trying to process new information and knowledge; all while attempting to get children ready for each activity within a tight timetable. Feeling overwhelmed or stressed due to the challenges of enabling participation has been well documented in the literature for parents of children with CCN (Bridges-Bond, 2011; Light, 1997; Piškur, Beurskens, Jongmans, Ketelaar, Norton, Frings, . . . Smeets, 2012). One positive aspect of camp is that parents were able to connect with others on a similar journey to them and discuss these feelings. There is some literature to show that exposure to diverse viewpoints and connecting with other families may enable parents to identify and articulate issues affecting their family and to feel more empowered to deal with them in a positive manner (Kingsnorth et al., 2011). Camp organisers need to know about these responses to ensure that future camps allow increased time in the timetable for transitions and mealtimes, along with time for families to relax and process the mental and emotional aspects of camp.

Although several parents reported feeling overwhelmed during the interviews, they spent more time discussing the positive emotional impact of feeling motivated, inspired and empowered. These positive emotions appeared to have arisen from several aspects of camp and demonstrate the interconnectedness of the camp experience. The parent education programme, being immersed in AAC and ALS, connecting with mentors, staff and other families with shared experiences, as well as enjoying camp and feeling a sense of belonging all appeared to contribute to these feelings.

Parents and siblings in this study felt motivated in regards to AAC implementation and learning. As per the Model of Parent Involvement (Fishman & Nickerson, 2015; Hoover-Dempsey & Sandler, 1995; Hoover-Dempsey et al., 2005), multiple factors appeared to contribute to increased motivation for parents. Camp provided the three basic psychological needs for motivation (Poulsen et al., 2015). Connecting with a diverse range of families, mentors and staff appeared to increase motivation, as everyone shared similar goals of implementing AAC (relatedness). There was increased motivation to continue to implement AAC at home, which appeared to be related to the parents' increased knowledge and skills (competence). Parents felt that they had gained knowledge but furthermore, they felt empowered to act upon this knowledge (autonomy) when they left camp. This finding is similar to previous literature, which identified that motivation to implement AAC can be gained through sharing experiences with others who are on the same journey and face similar challenges (Kingsnorth et al., 2011). In the context of this study, inspiration appeared to be a profoundly moving feeling, whereas motivation appeared to give parents the desire

to establish connections, implement AAC, and share their expectations with others after leaving camp.

The parents and siblings reported feeling inspired by the mentors which appeared to impact on their expectations of their child/sibling who uses AAC. They were then empowered to share their increased expectations with others. Empowerment is a strong predictor of positive parent outcomes relating to AAC (Minnes et al., 2015). It enables parents to make decisions for their child, have independence and feel that they have control as they deal with challenges related to raising their child who has CCN (Resch et al., 2010). This camp did not include school teams, as one of the previous studies (Myers, 2007) did. Therefore, it is important that parents felt empowered to share their increased expectations around AAC use and integration with their school teams.

Communication Outcomes

The findings pertaining to positive communication outcomes were similar to the outcomes reported in previous research. Although communicative competence was not directly measured, some parents and siblings reported increases in the children's linguistic competence over the short period of camp. This included increases in their frequency of AAC use and the number of words per phrase. These changes suggest that, for some children, the short but intense environment of camp may have had positive effects on their communicative competence. Similar findings were reported in several other camp studies (Berger & Feucht, 2012; Bruno & Dribbon, 1998; Bruno & Trembath, 2006; Dodd & Hagge, 2014; Kent-Walsh et al., 2010; Mbangamoh et al., 2008; Myers, 2007). An alternative

explanation is that it is possible that parents and siblings became more aware of their child/sibling's communicative competence, due to their increased knowledge and skills relating to AAC implementation.

Providing group therapy, where children who use AAC can learn from their peers, practice their social skills, generalize their learning and draw emotional support and encouragement from each other (Ballin & Balandin, 2007; Boyle et al., 2009; Hamm & Mirenda, 2006; Wilkinson et al., 1981) may account for some of the changes observed in communicative competence. Most of the children who use AAC reported in the post-camp survey that they had made friends; this factor may have supported their increased confidence in using their AAC system.

The communication outcomes noted may have arisen from the combination of explicit training, as well as immersion in ALS and AAC. Immersion is not just about children being surrounded by a language (i.e. AAC) but also about having opportunities to engage in interactions with communication partners within the experiences they encounter (Scope Australia, 2018). Explicit training in AAC and ALS was highly valued by the parents and siblings. A prominent finding in this study was that siblings wanted explicit training around AAC and ALS during camp. This finding aligns with the sibling training needs identified in the literature (Angelo et al., 1996; Fisher & Shogren, 2012; Land & Clendon, 2017; Linienfeld & Alant, 2005). The siblings were motivated to learn and increase in their confidence and knowledge of AAC within the immersion model. It is possible that if siblings were provided

with additional explicit training then they may have been able to further support their parents and siblings who use AAC to develop their communicative competence.

Despite the short duration of camp, it appears that many of the family support needs outlined in Chapter Two were able to be addressed during camp through immersion and explicit training. Similar findings were presented in previous camp research (Bruno & Dribbon, 1998; Bruno & Trembath, 2006; Kent-Walsh et al., 2010). Parents reported increased knowledge about AAC implementation and ALS skills. Some parents reported increases in their child's communicative competence but for others, it is possible that camp may not benefit the child who uses AAC directly at the time of camp, but the on-going support and increased skills and knowledge of their parents may be valuable.

Along with an increase in skills and knowledge, parents also reported that their expectations around AAC implementation had increased. Some parents expected that their child who uses AAC could achieve more (socially and academically) than they had previously, while some expected AAC to be integrated into daily family life more (using ALS strategies). Others expected that AAC would be used with more people than just the immediate family (e.g., extended family members and unfamiliar communication partners in the community).

All of the family members reported feeling motivated to continue to use AAC when they went home, as did most of the children who use AAC. As discussed in Chapter Two, it is critical that children who use AAC have access to their systems at all times and that their communication partners use ALS strategies and engage with them in reciprocal

conversations (Beukelman & Mirenda, 2013; von Tetzchner & Stadskeiv, 2016). Therefore, it is important that parents felt motivated to use AAC at the end of camp.

Unfortunately, some parents expressed disappointment in the content and/or depth of some aspects of the explicit training. Parents came to camp with a range of knowledge and experiences with AAC and the world of disability. Some parents reported that they had expected more in-depth technical training and less time to be spent on discussing feelings and support needs. They reported having already been a part of many disability support groups and did not feel they needed this type of support anymore. The feelings of disappointment are understandable considering the varied expectations parents came to camp with and the limited time with which to provide training. This could be addressed in the future through subsequent personalised training sessions at home or by offering a range of workshops they could sign up for.

Sociocultural Outcomes

Sociocultural factors are the beliefs, customs and practices, which affect thoughts, feelings and behaviours (ASHA, 2018). Two of the main sociocultural outcomes, which appear to have led to the positive experiences and perceptions reported by families at camp, were a sense of belonging and the holistic family-centred nature to camp. Having mentors support families through the camp also appeared to contribute to these sociocultural outcomes. Finally, identity appeared to have been developed as a result of attending camp.

Sense of belonging. There is a word in te reo Māori, “kotahitanga”, which seems to encompass the camp experiences for family even better than ‘a sense of belonging’. This word means a sense of ‘oneness’ or ‘a state of being at one’ and standing together in solidarity in collective action (Moorfield, 2018). A sense of belonging has also been highlighted in previous research. For example, Berger and Feucht (2012) shared several quotes about this topic. For example, one attendee said, “Don’t feel like an outcast”, another said, “It makes me feel normal” and another reported that, “We are like regular people” (p. 82) about how the camp experience gave them a sense of belonging. Parents in Myers (2007) study expressed an appreciation of spending time with other parents who understood the challenges of parenting a child who uses AAC. Kingsnorth et al. (2011) stated that parents might feel more empowered when there is a strong sense of belonging and mutual support. The connections between families, staff and mentors who attended KiwiChat Camp, combined with the feelings of inspiration and kotahitanga appeared to give families a resilience to continue implementing AAC, using ALS strategies and being involved in their child’s communication journey, despite this being perceived as hard work.

Holistic family-centred practice. As discussed in Chapter Two, holistic family-centred practice is essential to provide training, support and empowerment for the whole family (Bailey et al., 2006; McNaughton et al., 2008). This expectations was met for most families at camp. Families reported that they had connected with the staff and they acknowledged the hard work that had been put in to support each member of the family as a whole person with unique knowledge, needs and ideas. The results appeared to indicate that families felt that they were recognised as being the experts on their child/siblings’ abilities and needs.

Mentors. Connecting with the mentors affected many communication and sociocultural outcomes, such as increased expectations for parents after listening to what the mentors have achieved; increased knowledge about AAC and how beneficial ALS is for developing communicative competence for the siblings and parents; feeling a sense of belonging; and developing identity. Connecting with the mentors was perceived as enjoyable and worthwhile by most of the attendees. In addition to the enjoyment of these connections, making positive connections with other individuals who use AAC may be a protective factor against mental health risks and isolation. Although there is little research around the experiences of individuals with CCN, some researchers have identified that there is a need for the development of policies and methods of developing and maintaining social relationships that are rewarding and enriching (Ballin & Balandin, 2007; Cooper, Balandin, & Trembath, 2009b; Hamm & Mirenda, 2006) and camp may be a way of providing this. However, this is a postulation at this stage, as it has not been researched.

The results from this project indicated similar findings to those in the literature. Group mentoring has been shown to be an effective method of supporting younger or less experienced individuals to develop communicative competence and feel supported and part of a group (Ballin et al., 2011; Ballin et al., 2012; Ballin et al., 2013; Cohen & Light, 2000; Light et al., 2007; Mitchell, 2014). Camp mentors were only used in two camp studies previously, with positive effects (Berger & Feucht, 2012; Myers, 2007). Myers stated that an adult who used AAC “discussed with the participants and their parents how she had overcome her own communication challenges” but no further detail was provided about

how this was integrated into the camp programme (Myers, 2007, p. 268). Berger and Feucht (2012) mentioned that the camp director is a man who has used AAC for many years. As the director of the camp, he was involved in all aspects and delivered inspirational speeches to the attendees as well as answering questions and delivering communication training. The outcomes from both studies indicated that meeting the mentor was inspirational for the individual who used AAC and that it increased the expectations of some parents regarding what their child may be capable of in the future (Berger & Feucht, 2012; Myers, 2007).

Identity. The final sociocultural outcome for discussion is the development of personal identity. Identity development was only discussed by one parent in the interviews. However, it was felt to be of importance. For this one parent, multiple aspects of the camp experience appeared to contribute to the development of her daughter's identity as an individual who uses AAC. Connecting with other families, staff and especially with the mentors, being immersed in AAC and ALS, feeling a sense of belonging and enjoying camp, all appeared to impact on her daughter's perception of herself as an individual who uses AAC.

Identity was not asked about in the surveys or interviews, but it would be useful to explore this aspect further in future studies as it has implications for self-esteem, belief in oneself, confidence in using AAC, mental health, friendship and other areas (Allan et al., 2016). The idea of social identity was not discussed by any of the parents in this study. However, it is likely that camp affected this. Camp provided opportunities for individuals to connect with

groups who are similar to themselves, which is likely to have influenced how others perceive them based on which groups they gravitated toward.

As has been discussed in Chapter Two, few studies have investigated the development of identity for individuals who use AAC (Allan et al., 2016). One review suggested that further research is critical to understand how to support individuals to develop a positive self-identity; develop a positive outlook on life; and be included in their communities (Allan et al., 2016). Howery (2016) discussed the importance of intentionally supporting interactions between children who use AAC and other children who do and do not use AAC on developing identity and being able to be heard and seen. Camp may be one way of developing positive personal identities for children who use AAC.

Conclusion

This chapter discussed the study's key findings with reference to existing literature. Camp appeared to provide families with explicit knowledge through training and connecting with the mentors and staff; implicit knowledge through immersion and sharing experiences with other families who are on a similar journey; and the motivation, inspiration and empowerment to persevere with using AAC. Chapter Six will conclude this study with clinical implications and recommendations for future research.

Chapter Six: Conclusion

This chapter summarises the purpose, findings and rationale for this study. The trustworthiness of the findings are outlined, as well as the limitations of the research. Finally, the clinical implications and recommendations for future research are presented.

Purpose, Design and Rationale

Since the inception of KiwiChat Camp in 2010, families and TalkLink staff have anecdotally noted outcomes such as improved attitudes towards AAC, increased communicative competence, and positive experiences for children who use AAC and the whole family. During a review of the literature exploring the impact of AAC camps, startlingly few studies were found and they tended to be of poor quality. This study will begin to fill the void in the literature around AAC camps through answering the question “What are the experiences and perceptions of families (parents, siblings and children who use AAC) who attended KiwiChat Camp”. In addition, it aimed to investigate participant perspectives to inform the development of future camps. Both quantitative and qualitative methods via surveys, interviews, and focus groups were used to gather rich data to fulfil this aim.

The results of this study provide a New Zealand perspective on the experiences and perceptions of families (parents, siblings and children who use AAC) who attended camp. Results from this study indicated that attending a 5-day AAC focused camp resulted in positive experiences for families (parents, siblings and children who use AAC) and a number of beneficial communication and sociocultural outcomes were perceived. The results

highlighted the interconnectedness of each aspect of camp, meaning that individual aspects cannot be viewed on their own but must be regarded collectively.

Families enjoyed attending camp in general and enjoyed the activities, connecting with staff and other families who were using AAC and connecting with the mentors. An emotional response to camp was reported by parents. They reported feeling inspired, motivated and empowered at the end of camp, however, some also reported feeling overwhelmed during camp due to the fast-paced timetable and the amount of information and learning being processed.

Families in this study perceived several positive communication outcomes. Some parents and siblings perceived that their child/sibling who uses AAC increased in their linguistic competence, specifically the frequency and number of words per phrase used. They themselves experienced increased confidence, knowledge and expectations around AAC implementation and were motivated to learn more about AAC. They reported that engaging in a range of AAC training sessions, observing and participating in ALS and exposure to the spectrum of AAC systems and communication strategies that can be used with their children had a positive effect on their perceptions of implementing AAC.

Several sociocultural outcomes were noted in this study. Parents reported that they had increased expectations around AAC implementation for their family and the wider team, i.e. school teams and extended whanau and friends. They were empowered to implement AAC through connecting with mentors, staff and other families. One parent discussed the

positive development of her daughter's identity during camp. Not only did parents report these positive experiences and beneficial outcomes, but the siblings reported similar perceptions, especially highlighting their motivation to learn more about AAC. The children who use AAC enjoyed camp, benefited from meeting mentors and in most cases wanted to use their AAC system more after camp.

In summary, the results of this study indicated several unique benefits of using camp as a method for providing AAC intervention for the whole family. The literature shows that there are huge demands on families of children who have CCN and they often have difficulties finding time to implement AAC and increase their knowledge and expectations. Attending camp, even for a short period to time, resulted in a range of positive communication and sociocultural outcomes. Children, from a wide age range, who use a range of AAC systems and who have a range of diagnoses perceived camp positively and a number of communication and sociocultural outcomes were noted by their parents and siblings. Camp resulted in increased general, technical and individualised knowledge and skills and increased motivation and confidence to implement AAC for siblings and parents. Finally, camp was perceived to address a number of sociocultural support needs for the whole family, such as feeling a sense of belonging and developing identity. These benefits would likely only result from a camp, as the camp experience is unique: due to its connectedness, meeting others with similar needs, and its intensity. These findings are similar to those described in the literature. However, the interview methods used in this study provided more in-depth understanding of the sociocultural outcomes of camp. For example, siblings'

perceptions had not been included in the research previously and this provides a broader view of the impact of camp on the whole family.

Trustworthiness of Findings

Mills (2014) outlines three major components of trustworthiness in qualitative research that were considered during this project: credibility, transferability and confirmability. Credibility takes into account the complexity of data and involves establishing that the results are believable (Mills, 2014). Triangulation can be used to enhance the credibility of the data (Mills, 2014; Yin, 2014). This was achieved by examining multiple participant perspectives (parents, children who use AAC and siblings) and used a range of methods (surveys and interviews). The parent interviews provided greater depth to the parent perspectives. Integrating this data allowed the researcher to consider alternative explanations by comparing the variety of data sources and different methods with one another to cross-check the data (Mills, 2014). Triangulation was done during the GIA process and was checked by both supervisors regularly.

Transferability refers to the belief that findings from a qualitative study are context dependent (Mills, 2014). The goal is not to be able to generalise results to all camp attendees but to provide detailed descriptions of the context for consumers of the research to be able to identify with the setting (Mills, 2014). As transferability was low in some of the camp studies reviewed, information about the context (timetable, activities, attendees, etc.) has been provided in this project to allow readers to 'see' the setting.

Confirmability is the level of confidence to which the outcomes of a study can be confirmed and also the extent to which the researcher admits their own bias (Mills, 2014). A number of strategies enhance confirmability, such as triangulation and positionality (Mills, 2014; Yin, 2014). In this study my positionality as the researcher was acknowledged and reflected on throughout the project to demonstrate that findings emerge from the data and not my own bias. A detailed description of the research method was provided to enable the reader to confirm how the themes emerged from the data. The data from the interviews and short answer questions in the surveys allowed participants to describe their own experiences and then the inductive method of GIA and triangulation ensured that the results arose from the participants rather than from researcher bias. The results were checked by both supervisors and the procedures for checking and rechecking the data was documented.

Limitations

Although this research utilised credible and valid data collection and analysis procedures, there are some limitations that need to be considered when interpreting the findings.

Lack of maintenance and generalisation data. The major limitation of this study is the lack of maintenance and generalisation data following camp. The same limitation was identified in most of the camp studies reviewed in Chapter Two and the current study was not able to rectify this due to its limited scope. The parent interviews were completed within four weeks of camp and therefore some of this data may demonstrate maintenance and generalisation of the benefits of camp. However, these results must be interpreted cautiously. Therefore, it is not known whether the parents, siblings and children who use

AAC were able to maintain their feelings of motivation, inspiration and empowerment and continue to use AAC throughout the day, or whether the comments about 'AAC is hard work' surpassed the positive experiences when families were back in their everyday environments.

Following on from this, it is unknown how the perceived benefits of camp, such as increased AAC use, carried over to other environments such as school. All of the parents mentioned in their interviews that they felt empowered to discuss their increased expectations around AAC with school teams, whānau and friends. However, they also expressed that upskilling others was difficult. Future studies may wish to investigate methods of sharing information, goals and outcomes from camp with school teams and local SLTs.

Interconnectedness. As outlined in the results, one of the features that affected the outcomes was the interconnectedness of each of the aspects of camp. The camp programme incorporated a number of strategies, approaches and characteristics. For example, direct explicit teaching, as well as immersion in ALS and other communication strategies, were provided to parents. Families connected with other families, mentors and staff, each of whom appeared to impart different insights, knowledge and ideas. The children who use AAC participated in explicit small group intervention, unplanned one-to-one sessions and whole group support. Each aspect of the camp experience is inherently difficult to tease apart, meaning that it is difficult to determine which specific aspects produced each of the outcomes. Although this study did not aim to attribute a causal relationship for each outcome, future studies may wish to explore these aspects separately

through in-depth interviews with family members, field observations or other research methods.

Method and instruments. This project aimed to use more robust research methods than those previously published to ensure that the study resulted in meaningful clinical implications. The researcher attempted to integrate feedback instruments from overseas camps as well as TalkLink's forms when creating the research instruments for this study. However, this was not possible as the overseas camp organisers did not reply to emails or replied but reported that they did not utilise feedback forms at their camps. The pre-and-post camp survey questions were peer-reviewed but in hindsight, some improvements could have been made. For example, the questions in the pre-and-post surveys were not well-aligned and results could not be analysed across time for each participant.

Self-selection bias. All of the families chose to attend camp and participate in this project, which may have introduced a potential bias. It is important to acknowledge that families were already more likely to experience and perceive camp positively, as they had the initial motivation to fill in several forms, take time off work and pay for camp and travel costs to attend. Before camp began, families understood that they would need to be committed and actively participate in all activities. Self-selection bias may have resulted in data that was positively skewed towards the benefits of camp. However, this is always going to be the case for camp research.

Clinical Implications

This study has presented the positive perceptions and experiences of families who attend camp and has implications for using similar camp style AAC intervention methods in the future. Firstly, camp should be enjoyable. Enjoyment may be achieved through planning age-appropriate, highly motivating, accessible activities for the whole family; ensuring enthusiastic staff and volunteers are available to support families through the camp experience; and providing food that caters to all diets. The timetable needs to be adjusted so that families have time to process their multiple and complex emotional reactions to camp, in addition to processing all of the information they learn. Providing a mixture of explicit parent training programmes, as well as immersion of AAC through ALS strategies, appeared to be an effective method of increasing AAC knowledge, as well as motivation, inspiration and empowerment. Organizers should integrate explicit training programmes (around AAC and how to be a good communication partner) for siblings, as well as continuing to include AAC immersion. Effort should be made to invite mentors to camps which focus on AAC, to ensure that each family member has the opportunity to connect with a mentor whom they can learn from. Families appeared to benefit from meeting a range of families from a range of backgrounds. This aspect of camp produced a sense of belonging and therefore organisers may wish to ensure that when families are selected to attend, they represent a range of geographical regions; ages; cultures, and types of AAC systems so that families have the opportunity to connect with, and learn from, diverse families.

Implications for Future Research

This project contributed to the very small existing body of research on the effect of camp on AAC implementation, taking the number of studies from seven to eight. Considering that AAC camps are run throughout the world, more research is required to explore the benefits of camp from multiple viewpoints. In addition to the recommendations for future research briefly outlined in the limitations, two further suggestions are presented.

Cost-effectiveness. Although this study did not aim to investigate the cost-effectiveness of camp, future studies may wish to investigate this. Running a camp is an expensive process, both in monetary and time resources. It is important that the number of hours required to run a camp be compared to the number of hours of individual or small group training sessions it would take to generate similar outcomes. The uniqueness of the camp experience may mean that it is not comparable to individual or small group training, as characteristics such as connecting with the mentors and networking with other families may not be achievable in contexts other than camp.

It would be beneficial to explore the frequency and duration of a camp required to maximise the results. For instance, a 3-day camp may have the same perceived impact as a 5-day camp and would, therefore, be a more cost and time effective method of providing the camp style intervention. Researchers may also want to investigate whether attending camp had a cumulative effect on AAC use, i.e. whether attending camp once has the same effect as attending each year for three years. Both of these are important aspects

to investigate, as government-funded services need to be accountable and ensure that time and resources are cost-efficient.

Voice of individuals who use AAC. In this study, effort was made to ensure that the voice of children who use AAC was heard as per recommendations in the literature (Doell & Clendon, 2018). This study can be used to guide future studies in this process. However future researchers may wish to explore alternative, more creative methods of gaining this information. Talking Mats (Talking Mats, 2018) and interviews may allow for more rich narratives to be expressed. It may also be beneficial to interview mentors to investigate their observations and ideas about how to maximise the camp experience, as they have gone through similar challenges to the children who use AAC when attending camp.

Challenges of interviewing siblings. Steps were taken to ensure that the siblings were able to provide comprehensive and in-depth information during their interviews. For example, they were interviewed in groups with their peers and their group leader who they had built rapport with after spending five days at camp; the length of the interviews did not exceed 30 minutes; the interview questions were written at an age-appropriate level; and they were interviewed in a location of their choosing (sitting on the grass in the sun). However, there were some challenges inherent to interviewing children. The younger children, in particular, appeared fatigued and distracted after 10-15 minutes. This may be because it was the end of camp and many of the children stayed up late the night before to attend the camp show. Some children may also have felt shy or less confident to share their experiences or perceptions in the group setting. Future studies may wish to use visual

supports, such as Talking Mats (Talking Mats, 2018) to structure the interviews and ensure that the interviewer also builds rapport with the siblings before conducting the interview.

Other stakeholders. This study only explored the experiences and perceptions of children who use AAC and their families. Extended whānau (e.g. grandparents, aunts and nephews) attended camp, although their perceptions and experiences were not investigated in this study. Future studies may wish to investigate the impact of camp on AAC implementation on the wider family, as some children often spend time with grandparents or other family members. Additionally, it would be beneficial to explore the perceptions and experiences of TalkLink staff and volunteers. It is hypothesised that outcomes such as increased job satisfaction, increased empathy and confidence, increased knowledge of implementing AAC and providing AAC training may result from camp.

Assessment. This study was focused on exploring experiences and perceptions. Therefore pre-and-post camp communicative competence assessments were not carried out. Future camps may wish to collect additional data. They may wish to use a different research design to assess changes in communicative competence, as some of the previous camp studies have done. However, this is challenging over such a short timeframe as children with CCN tend to gain communicative competence over time (Beukelman & Mirenda, 2013). New assessment tools may need to be created to capture the subtle changes over the short period.

Concluding Thoughts

The primary goal of all AAC interventions is to increase the communicative competence, participation, learning and wellbeing (self-esteem and confidence) of children who use AAC and support their teams. Teams, which may include family, school staff and others, need to have the skills and knowledge to partner with these children to achieve these goals. In this study, the results supported the use of camps to provide holistic AAC intervention for the whole family as indicated by the positive experiences and perceptions of families who attended KiwiChat Camp. Recommendations for future studies have been identified. The findings from this study may inform future research which will allow the data collection tools to be improved upon to continue to investigate the wider benefits of AAC camps.

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Appendix

Note. Jessamy married between the start and completion of this thesis, therefore both names (“Jessamy Amm” and “Jessamy Bell”) are used in the Appendices.

Appendix A: Summary of AAC Camps

	Live in AAC Camps				Day Stay AAC Camps		
	Mbangamoh 2008	Berger 2011	Bruno 1998	Bruno 2006	Dodd 2014	Myers 2007	Kent-Walsh 2010
Aims	To provide information about an experience for adults who use AAC and attend a Camp Courage summer program	To recount of author’s experiences	To determine whether a parent training program, combined with an intervention program for their children, could affect a positive change in parents’ perceptions of device operation and management skills, AAC interaction skills and their child’s AAC device performance.	To explore whether syntactic performance improved following a weeklong therapy program using ALS and whether this performance differed when using a manual communication board or a SGD	To explore the effects of an AAC-based intervention provided in a camp format and examine strategies to monitor and document progress	To explore effective approaches, content and contexts for supporting communication (including oral language, literacy, and technology skills) among AAC users.	To use the ImPAACT programme to teach communication partners techniques designed to facilitate the communication skills of children with CCN
Participants	11 campers – no information on diagnosis,	18 campers. Some anecdotal information	14 campers, 9F 5M – 16 parents who answered questionnaires	9 campers – no information on parents	29 SLT students filled in surveys	4 campers, 3F 1M	10 campers, 3F 7M – 10 parents who answered question

	age, gender, etc.	about type of disability			30 campers, 18M 12F			
Age (years)	Young adults – 18 years and up – exact ages unknown	13-23	6-14	4-14	5-22	5-9	3-7	
Disabilities	No specified	Most CP, 1 ASD	CP, TBI, ADHD (4 walking/10 wheelchair)	DS, CP, other syndromes/disorders	ASD, CP, DS, GDD, others	CP, DS	Apraxia, ASD, DS, CP	
Ethnicity	No info	No info	No info	No info	Range	No info	No info	
Device/language system	DynaVox Vmax, DynaVox Palmtop Impact, DynaVox DV-4, PRC ECO-14, PRC Pathfinder, Assistive Technology Mini Merc and the Blink Twice Tango! board	Some direct access, some eye gaze but not explicitly stated, Tobii, communication board	Powerbook with Speaking Dynamically, TM1 Powerbook with Talk:About, Liberator, TouchTalker, DynaVox, communication board	DynaMyte, PathFinder, E-Talk, communication board, DynaVox	No info	Macaw3 x3, one unnamed device, communication board	TechSpeak, BlueBird, Vantage, communication board	
Duration	1 week live in but number	5 days live in	5 days live in	5 days live in	24 hours over 2 weeks – day programme	4 weeks intensive – five 2hour sessions	2-week day camp - Monday, Wednesday, and	

	of days not specified					for 4 weeks plus 4 follow up visits to school	Friday afternoons for 2 consecutive weeks, for 3 hours per day, except the last day of camp
Location	One camp where everyone stays together and can connect	One camp where everyone stays together and can connect	One camp where everyone stays together and can connect	One camp where everyone stays together and can connect	4 locations across the state so not all students met each other	One camp where everyone stays together and can connect	One location but did not stay overnight
Family involvement	Only camper	Parents and campers but no siblings are listed. No one from school team.	Parents and campers. Siblings invited.	Parents and siblings and campers. No one from school team.	Only camper and SLT student	Parents and campers – no siblings or school team members but there was follow up with the schools	Parent and camper
Intervention	Some descriptive information about intervention but not details and could not be replicated –	Some description of the layout of the therapy and ‘camp events’ – split into two groups each morning and then swap after an hour. Language Time	Parent training program comprised of (a) needs focused device training and (b) interaction training. Children received 40 minutes of daily	2x 45min therapy session for each of the 5 days – shared book and art activity. No parental training	Child-centred naturalistic approach – modelling, self-talk, aided language stimulation, expansion 1:1 therapy input	Child-centred naturalistic approach – modelling, self-talk, ALS. Required family involvement and provided follow-up visits to schools to share	The children did not receive any specific AAC instruction during the camp activities, whereas caregivers spent the majority of each day

	no examples provided.	run by an SLT – aims not stated	intervention in small group settings. Individual short-term intervention goals were defined by parents on the intake forms. In addition to the small group sessions, children’s activities were designed to increase functional device use throughout the day.			effective instructional strategies with staff.	participating in training sessions with the instructors Then parents participated in shared storybook reading with their child using the training they had received.
Data collection method	Campers were videotaped the first day of camp with a trained conversational partner asking questions but providing no	Recount of authors experiences and field notes	Questionnaires used at three intervals describing (a) parents skills in device operation and management, (b) their augmentative and alternative	Pre-test administered at beginning of camp Post-test assessment administered 5 days later.	Online post-camp survey of SLT students completed in approximately 10-15 minutes	Pre-intervention questionnaires completed by parents, pre-and post-intervention language, literacy and technology assessments, detailed field observations,	Pre- and post-instruction measures were taken for both the caregivers and the children. For each 10-minute story reading session, the percentage of strategy steps

additional prompts. Similar questions were asked and videoed on the last day of camp. Videos were analysed for mean length of utterance (MLU), speed in words per minute (WPM) and social acts. Pre-camp and post-camp surveys completed by campers and caregivers

communication (AAC) interaction skills, and (c) their children’s AAC device performance.

Data were collected at three intervals: upon arrival at camp, at the conclusion of camp, and 6 months following camp.

work samples, and video-recording collected during intervention. Quantitative measures, including pre and post-intervention language and literacy assessments and a survey designed to measure changes in the children’s perceptions of themselves as speakers, readers and writers during the study.

correctly implemented was calculated for the caregivers, and the number of multi-symbol messages produced was calculated for the children. Parents completed questionnaires about their experiences with the instructional program.

Results

Some anecdotal information about one of the campers is described but there is no

Quotes from campers and questions asked by the facilitator. There are some quotes from campers about what camp

Parents perceived a positive change in their device operation, management, interaction skills and positive

All participants increased MLU and grammatical complexity. Only 2 students maintained these

All made positive gains; noted both in the areas of communicative behaviours and pragmatic use. Camp attendees increased total

Formative and summative assessment measures revealed that all four participants made progress

Statistically significant difference between pre and post use of techniques. 9 children improved on

	information about the survey results. Campers increased MLU, rate of speech and communication acts in a 10min conversation.	means to them, e.g. 'don't feel like an outcast'.	changes in their children's AAC performance. Six months following camp, parents had maintained the positive changes made at camp. No increase or decrease in skills were noted.	gains when back at school.	number of different words used, MLU and range of language functions used.	during intervention. Two students maintained these gains into the follow-up period, whereas two did not. Each pair seemed to share similar characteristics.	their combination of symbols during the book reading activity and 1 did not.
Maintenance	No info	No info	No info	Stated two students maintained but no information about how they came to this conclusion or when they re-tested them	No info	Two maintained, two lost gains. 4 follow up visits 6-8 weeks after the intervention to teachers to share instructional approaches/portfolio work/videos of campers working.	No info

Appendix B: KiwiChat Camp Timetable 2016

Time	Day 1 Friday	Day 2 Saturday	Day 3 Sunday	Day 4 Monday	Day 5 Tuesday
8:00-8:30	Health and safety briefing at breakfast	Breakfast	Breakfast	Breakfast	Breakfast & post-camp surveys
8:30-9:00	Cabin and ablutions tidy up	Cabin and ablutions tidy up	Cabin and ablutions tidy up	Cabin and ablutions tidy up	Cabin and ablutions tidy up
9:00-10:00	Talklink Campers: A & B: Youtube choosing C & D: Fancy dress & super props	Talklink Campers: A & B: Face painting & photo booth C & D: Art/Art/Make a poppy/wreath	Talklink Campers: A & B: Face painting & photo booth C & D: Art/Art/Make a poppy/wreath	Talklink Campers: Group D one teaching an at a Super Hero	Talklink Campers: Group D one teaching an at a Super Hero
9:00-10:00	Siblings: A: Parachute games B: (B&W) Human Football C: Archery	Siblings: A: Face painting and Artery B: Bowling/Blech Climbing C: Archery	Siblings: A: Face painting and Artery B: Bowling/Blech Climbing C: Archery	Siblings: A: Learn a Super Hero Dance! B: Low Repetition/Research Interview C: Research Interview/Low Repet	Siblings: A: Learn a Super Hero Dance! B: Low Repetition/Research Interview C: Research Interview/Low Repet
9:00-10:00	Parent and Caregiver Workshops: Special Guest Presentation	Parent and Caregiver Workshops: AAC Mentor Presentations	Parent and Caregiver Workshops: AAC Mentor Presentations	Parent and Caregiver Workshops: Editing, programming and software training	Parent and Caregiver Workshops: Editing, programming and software training
10:00-10:30	Morning Tea	Morning Tea	Morning Tea	Morning Tea	Morning Tea
10:30-11:30	Talklink Campers: A & B: Fancy dress & super props C & D: Youtube choosing	Talklink Campers: A & B: Art/Art/Make a poppy/wreath C: Face painting with photo booth	Talklink Campers: A & B: Art/Art/Make a poppy/wreath C: Face painting with photo booth	Talklink Campers: Who Wants to be a Millionaire?	Talklink Campers: Who Wants to be a Millionaire?
10:30-11:30	Siblings: A: Jeremy Iyts & Super props B: Artery C: BMX/Human Football	Siblings: A: Artery/Ringground B: Flying Footloose Hokey C: Bowling/Blech Climbing	Siblings: A: Artery/Ringground B: Flying Footloose Hokey C: Bowling/Blech Climbing	Siblings: A: Who wants to be a Millionaire?	Siblings: A: Who wants to be a Millionaire?
10:30-12:30	Parent and Caregiver Workshops: Special Guest Presentation	Parent and Caregiver Workshops: AAC Mentor Presentations	Parent and Caregiver Workshops: AAC Mentor Presentations	Parent and Caregiver Workshops: Editing, programming and software training	Parent and Caregiver Workshops: Editing, programming and software training
11:30-12:30	Camp Boobs - All kids	Camp Boobs - All kids	Camp Boobs - All kids	Camp Boobs - All kids	Camp Boobs - All kids
12:30-1:30	Lunch	Lunch	Lunch	Lunch	Lunch
1:30-2:30	Prep for Talent show	Prep for Talent show	Prep for Talent show	Prep for Talent show	Prep for Talent show
2:30-3:30	Family activities: Hydrslide, Hot Pool, Ranshate games, Booba	Family activities: Hydrslide, Hot Pool, abarbling, Booba	Family Activities: Hydrslide, Hot Pool, abarbling, Booba	Family Activities: Hot Pool, Flying Footloose and Booba available.	Family Activities: Hot Pool, Flying Footloose and Booba available.
3:30-4:00	Afternoon Tea	Afternoon Tea	Afternoon Tea	Afternoon Tea	Afternoon Tea
4:00-5:30	Talklink staff and volunteers arrive	Free Family time: Pool, Booba, Artery	Free Family time: Pool, Booba, Artery	Free Family time: Pool, Booba, Artery	Free Family time: Pool, Booba, Artery
5:30-6:30	Arrival and settle in	Dinner	Dinner	Dinner	Dinner
7:00-	Movie night! Teachers available for parent workshop - Library	Disco!	Disco!	Super Hero Talent Show	Super Hero Talent Show
					Depart

Appendix C: Information



INFORMATION SHEET FOR PARENTS
INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Researcher(s) Introduction

This project is being carried out by Jessamy Amm, a Masters student in the Speech-Language Therapy program at Massey University, Auckland, under the supervision of Dr Sally Clendon and Dr Elizabeth Doell. Jessamy is currently employed as a Speech Language Therapist at TalkLink Trust.

Project Description and Invitation

The aim of this project is to explore the views and experiences of families attending the KiwiChat Camp for children who use augmentative and alternative communication (AAC). We know that children who use AAC require significant input in order to learn to use their AAC systems independently and spontaneously and there are many different methods of providing this teaching and support. There is very little understanding of how an intensive camp might benefit children who use AAC and their families.

This is a **four-part project**:

1. Parents – Pre-camp and Post-camp surveys

Parents/caregivers will be asked to complete a pre-camp and a post-camp survey. In both surveys, you will be asked about your confidence in supporting your child who uses an AAC system. In the post-camp survey, you will also be asked to discuss your experiences at camp and whether you found it beneficial.

2. Parents - Follow Up Interviews

Three parents will be asked to complete a Follow-Up Interview via telephone/skype. This interview will also be focused on your experiences at camp.

3. Children who use AAC – Surveys

Your child who uses AAC will be asked to complete a survey on the final morning of camp. S/he will be asked about the camp experience, e.g., what they learned, what they enjoyed.

4. Siblings – Group Interviews

If you have other school-aged children attending camp, then they will be asked to participate in a small group interview with similarly aged children. They will be asked about their experiences having a sibling who uses AAC, their confidence helping their sibling to use their AAC system, and their experiences at camp, e.g., what they learned, what they enjoyed.

I would be very grateful if you would consider participating in some or all four parts of the project.

Participant Identification and Recruitment

Ann Smail, General Manager, TalkLink Trust, has given permission for this project to take place. The Camp Organiser, has been asked to send this Information Sheet and the Consent Forms to any families who are attending KiwiChat camp from 22 to 26 April 2016.

Project Procedures

1. Parents – Pre-camp and Post-camp surveys and Interviews

The pre-camp survey will be completed online. The survey can be completed at a time that is convenient to you and will take approximately 20 minutes. If you are unable to complete the online version, a paper-based copy will be provided on the first day of camp.

The post-camp survey will be paper-based. This will be completed on the last morning of camp and will take you approximately 30 minutes.

2. Parents - Follow Up Interviews

Three parents will be asked to complete a follow-up interview via telephone/skype when you are back at home. These parents will be randomly selected from the list of parents who indicate that they would be willing to participate in this stage of the project during the pre-camp survey. These interviews will take approximately 30 minutes, and will occur within three weeks of returning home from camp. Liaison with the researcher will occur to find a time that is suitable for both the parents and researcher. The interviews will be digitally recorded for later transcription. You will have an opportunity to read and approve the transcript.

3. Children who use AAC – Surveys

The survey for children who use AAC will be completed on the last morning of camp and will take approximately 20 minutes. Speech and language therapy (SLT) students from Massey and Auckland universities are attending camp. These students will support your child to complete the survey. They will be provided with training to ensure that they provide minimal appropriate prompts. The survey will be adapted with communication symbols.

4. Siblings – Group Interviews

The researcher will conduct the sibling interviews on the last full day of camp. They will take approximately 30 minutes. They will be carried out in the groups that the siblings will have been in for the entirety of camp. The group's leader will be present. Interviews will be digitally recorded for later transcription.

Other Considerations

All KiwiChat Camp attendees will be invited to fill out surveys to assist with planning for future camps, therefore if you decide not to be involved in this research, the surveys will only be collected by the Camp Organiser, and not by the researcher. These surveys will not be used as part of the research project.

The surveys and interviews will not be anonymous however code numbers will be used to ensure that participants' identities are protected. All of the information that you provide will be stored in a locked office at Massey University or TalkLink Trust Auckland office. Only the researchers and the Camp Organiser, and researcher's supervisor, Sally Clendon, will have access to the information to plan for and improve future camps.

When the project is finished, the results of the study may be published in journals or presented at conferences; however, the information will not include the names of any of the participants. A summary of the research findings will be sent to you and TalkLink.

The information will be kept for 5 years following the completion of the final publication. When disposed of, the University confidential waste service will be used for printed materials, and audiotapes will be wiped.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Withdraw from the study at any time prior to the commencement of data analysis and have any data pertaining to you or your children destroyed;
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that your name or your children's names will not be used unless you give permission to the researcher;
- Be given access to a summary of the project findings when it is concluded.

This study is under the supervision of Massey University, not TalkLink Trust. Therefore, your participation or non-participation in this project will not impact on the services you receive from TalkLink Trust (now or in the future). Ann Smail, General Manager, TalkLink Trust, has given permission for this project to take place. If there are any questions about this you may contact the researcher's manager at TalkLink Trust (Ann Smail 09 5571201).

We understand that some of the questions in this survey may have caused an emotional reaction. If you feel in any way upset or concerned, please talk with a support person (e.g. your TalkLink Speech Language Therapist or a family member), the Camp Organiser, 095571216, 0274744559) or the researcher (Jessamy Amm, 095571214, 0210444681).

Project Contacts

If you think you might be interested in participating in this project, please complete the attached consent form and return it to Jessamy

jessamy.amm.1@uni.massey.ac.nz

If you have any questions relating to the project, please call Jessamy Amm on **0210444681** or Dr Sally Clendon on **414 0800 Ext. 43537**.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application MUHECN (NOR 16/04). If you have any concerns about the conduct of this research, please contact Dr Andrew Chrystall, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43404, email: humanethicsnorth@massey.ac.nz

Thank you for considering this project.

This information sheet is for you to keep

Jessamy Amm
Masters Student
Speech-Language Therapy Program
Institute of Education
Massey University

Appendix D: Information Sheet for Older Siblings



INFORMATION SHEET FOR OLDER SIBLINGS
INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Researcher(s) Introduction

This project is being carried out by Jessamy Amm, a Masters student in the Speech-Language Therapy program at Massey University, Auckland. Jessamy is being supervised by Dr Sally Clendon and Dr Elizabeth Doell. Jessamy is currently working as a Speech Language Therapist at TalkLink Trust.

Project Description and Invitation

The aim of this project is to talk to the families attending the KiwiChat Camp for children who use augmentative and alternative communication (AAC) about their experiences. We know that children who use AAC need extra help to learn to use their AAC systems. We want to find out whether a camp, such as KiwiChat Camp, might help children who use AAC and their families.

As part of this project, Jessamy will conduct small group interviews with siblings. She will ask you about your experiences having a brother or sister who uses AAC, how confident you feel in helping them to use their AAC system, and your experiences at KiwiChat Camp, e.g., what you learned, what you enjoyed. We would be very grateful if you would consider being part of this project.

Participant Identification and Recruitment

Ann Smail, General Manager, TalkLink Trust, has given permission for this project to take place. The Camp Organiser has been asked to send this Information Sheet and the Consent Forms to any families who are attending KiwiChat camp from 22 to 26 April 2016.

Project Procedures

The group interview will last approximately 30 minutes. Jessamy will conduct the interviews on the last full day of KiwiChat Camp in the groups that you have been in for camp. The group leader will be present. Interviews will be recorded.

Other Considerations

All of the information that you provide will be stored in a locked office at Massey University or TalkLink Trust Auckland office. Only the researcher, her supervisor, Sally Clendon, and the Camp Organiser, will have access to the information. The Camp Organiser will use the information to plan for and improve future camps.

When the project is finished, the results of the study may be published in journals or presented at conferences; however, the information will not include any names. A summary of the research findings will be sent to your family and TalkLink.

The information will be kept for 5 years after the findings have been published. The printed materials will then be destroyed, and audiotapes will be wiped.

Participant's Rights

You don't have to take part. If you decide to take part, you have the right to:

- Ask any questions about the study at any time
- Decide not to answer any particular question in the interview;
- Pull out of the study at any time before the data analysis begins and have any information about you destroyed;
- Give information on the understanding that your name will not be used unless you give permission to Jessamy;
- Be given a copy of the project findings when it is finished.

This study is being supervised by Massey University, not TalkLink Trust. Therefore, whether you take part in this project will not affect the services your brother or sister receives from TalkLink Trust (now or in the future). If you have any questions about this, you may contact Jessamy's manager at TalkLink Trust (Ann Smaill 09 5571201).

If you feel upset or concerned about anything in the interview discussions, please talk with your parents or a support person (e.g. your TalkLink Speech Language Therapist or a family member).

Project Contacts

If you think you might be interested in this project, please complete the attached consent form and ask your parents to return it to Jessamy at: jessamy.amm.1@uni.massey.ac.nz

If you have any questions relating to the project, please call Jessamy Amm on **0210444681** or Dr Sally Clendon on **414 0800 Ext. 43537**.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application MUHECN (NOR 16/04). If you have any concerns about the conduct of this research, please contact Dr Andrew Chrystall, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43404, email: humanethicsnorth@massey.ac.nz

Thank you for considering this project.

This information sheet is for you to keep.

Jessamy Amm
Masters Student
Speech-Language Therapy Program
Institute of Education
Massey University

Appendix E: Consent Form – Parents



CONSENT FORM - PARENTS

This consent form will be held for a period of five (5) years from the date of the last publication

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

Please place a tick in the box if you agree to the following:

1. Parents – Pre-camp and Post-camp Surveys and Parent Interview

- I agree to participate in the pre-camp parent survey.
- I agree to participate in the post-camp parent survey.
- I understand that TalkLink routinely surveys camp attendees to evaluate camp and assist with planning for future camps and understand that TalkLink will have access to the anonymized survey responses.
- I am willing to participate in a follow-up interview after returning home from KiwiChat Camp.
- I agree to be audio recorded during the follow-up interview.

2. Children who use AAC – Surveys

- I agree that my child, who uses an AAC, may participate in this study under the conditions set out in the Information Sheet.
- I give permission for the student speech-language therapy volunteers to support my child to complete their survey.

3. Siblings – Group Interviews

- I agree that my child/children (between the ages of 5 and 15 years old) may participate in this study under the conditions set out in the Information Sheet.
- I agree to my child/children being audio recorded during the sibling interview.

Signature:

Date:

.....

Parent/caregiver full name

.....

AAC device user's name:

.....

Sibling's name/s:

.....

Appendix F: Consent Form – Older Siblings



CONSENT FORM – OLDER SIBLINGS

This consent form will be held for a period of five (5) years from the date of the last publication

I have read the Information Sheet and the study has been explained to me. My questions have been answered, and I understand that I may ask further questions at any time.

Please place a tick in the box if you agree to the following:

Siblings – Group Interviews

- I agree to be part of this study under the conditions explained in the Information Sheet.
- I agree to be audio recorded during the interview.
- I give permission for the group leader to be present during the sibling group interview.

Signature:

.....

Date:

.....

Full name

.....

Appendix G: Verbal Assent Script

**Verbal Assent Script**

Children between the ages of 5-15 will be asked for their consent before each session starts.

The following script will be used. Their parents will also sign a Consent form.

“Hi, my name is Jessamy. I am involved in a small research project and would like you to help me. I would like to find out what you thought of coming to KiwiChat Camp and what it’s like to have a brother or sister who uses a communication device. You can choose to leave the group at any time. Would you be happy to help me out? (if they give consent) Would it be ok if I use my phone to record our chat?”

Appendix H: Pre-camp Survey for Parents



PRE-CAMP SURVEY FOR PARENTS/CAREGIVERS

This project is being carried out by Jessamy Amm, a Masters student in the Speech-Language Therapy program at Massey University, Auckland, under the supervision of Dr Sally Clendon and Dr Elizabeth Doell.

The aim of this project is to explore the views and experiences of families attending the KiwiChat Camp for children who use augmentative and alternative communication (AAC). We know that children who use AAC require significant input to learn to use their AAC systems independently and spontaneously and there are many different methods of providing this teaching and support. There is very little understanding of how an intensive camp might benefit the AAC user and their family.

This survey aims to investigate parent/caregiver knowledge and confidence in supporting their child who uses AAC before attending KiwiChat Camp.

If you have any questions relating to the project, please contact Jessamy Amm on 0210444681 or jessamy.amm.1@uni.massey.ac.nz. Alternatively, you can contact Dr Sally Clendon on 414 0800 Ext. 43537.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application MUHECN (#). If you have any concerns about the conduct of this research, please contact Dr Andrew Chrystall, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43404, email: humanethicsnorth@massey.ac.nz

Thank you for your participation in this project.

Please provide the following information:

- Parent name:
- Child who uses AAC name:
- Diagnosis:
- Age of child who uses AAC:
- Type of AAC system:
- Siblings names:
- Ethnicity:

Please rate each of these questions using the scale provided:

I feel confident in using my child’s communication system

strongly agree agree neutral disagree strongly disagree not applicable

I feel confident in creating opportunities for my child to communicate

strongly agree agree neutral disagree strongly disagree not applicable

I feel confident in programming/editing my child’s communication device

strongly agree agree neutral disagree strongly disagree not applicable

I feel connected to other families of children who use AAC devices

strongly agree agree neutral disagree strongly disagree not applicable

I feel confident in prompting my child to use their communication device

strongly agree agree neutral disagree strongly disagree not applicable

My child needs support to learn to use their communication device

strongly agree agree neutral disagree strongly disagree not applicable

I feel confident with modelling language on my child’s communication device

strongly agree agree neutral disagree strongly disagree not applicable

I have interacted with older children or adults who use communication devices.

strongly agree agree neutral disagree strongly disagree not applicable

Please use the text box below to answer the following questions (there is no word limit):

My expectations for camp are:

.....
.....
.....

I hope to achieve the following at camp:

.....
.....
.....

Please briefly summarise any training/support/experience you have had in supporting your child to use their communication system, e.g. training from TalkLink, courses run by AAC therapists, attending KiwiChat Days, etc.:

.....

.....

.....

Please write any other thoughts about your participation in KiwiChat Camp that may not have been covered in the previous questions:

.....

.....

.....

Thank you for taking the time to complete this survey.

We understand that some of these questions may have caused an emotional reaction. If you feel in any way upset or concerned, please talk with a support person (e.g. your TalkLink Speech Language Therapist or a family member), the Camp Organiser (1234567) or the researcher (Jessamy Amm, 095571214, 0210444681).

Please remember that your anonymised responses will be shared with the Camp Organiser, to assist with planning and improvement of future camps.

Appendix I: Post-camp Survey for Parents

**POST-CAMP SURVEY FOR PARENTS/CAREGIVERS**

This project is being carried out by Jessamy Amm, a Masters student in the Speech-Language Therapy program at Massey University, Auckland, under the supervision of Dr Sally Clendon and Dr Elizabeth Doell.

The aim of this project is to explore the views and experiences of families attending the KiwiChat Camp for children who use augmentative and alternative communication (AAC). We know that children who use AAC require significant input to learn to use their AAC systems independently and spontaneously and there are many different methods of providing this teaching and support. There is very little understanding of how an intensive camp might benefit the AAC user and their family.

This survey aims to investigate parent/caregiver knowledge and confidence in supporting their child who uses AAC after attending KiwiChat Camp.

If you have any questions relating to the project, please contact Jessamy Amm on 0210444681 or jessamy.amm.1@uni.massey.ac.nz. Alternatively, you can contact Dr Sally Clendon on 414 0800 Ext. 43537.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application MUHECN (#). If you have any concerns about the conduct of this research, please contact Dr Andrew Chrystall, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43404, email: humanethicsnorth@massey.ac.nz

Thank you for your participation in this project.

Parent name:

Name of child who uses AAC:

Please rate each of these questions using the scale provided:

The camp activities were appropriate for my child.

strongly agree agree neutral disagree strongly disagree not applicable

My child enjoyed the camp experience.

strongly agree agree neutral disagree strongly disagree not applicable

The camp experience was helpful to our family.

strongly agree agree neutral disagree strongly disagree not applicable

I feel that my child/children were safe at camp.

strongly agree agree neutral disagree strongly disagree not applicable

My child's confidence in using his/her communication device improved.

strongly agree agree neutral disagree strongly disagree not applicable

My child gained more confidence in initiating communication using his/her communication device.

strongly agree agree neutral disagree strongly disagree not applicable

My child improved his/her ability to maintain a conversation using his/her communication device.

strongly agree agree neutral disagree strongly disagree not applicable

I feel more confident in my ability to help my child communicate.

strongly agree agree neutral disagree strongly disagree not applicable

I feel the camp experience provided me with tools to help my child become a better communicator.

strongly agree agree neutral disagree strongly disagree not applicable

I am satisfied with the camp experience.

strongly agree agree neutral disagree strongly disagree not applicable

The parent workshops in the morning were useful and I gained knowledge and confidence because of them.

strongly agree agree neutral disagree strongly disagree not applicable

The parent group trainers/therapists were skilled in facilitating group discussion.

strongly agree agree neutral disagree strongly disagree not applicable

Networking with other families who have a child who uses a communication device was useful.

strongly agree agree neutral disagree strongly disagree not applicable

I feel more connected with other families (compared to before I came to KiwiChat Camp) and will continue these connections.

strongly agree agree neutral disagree strongly disagree not applicable

Interacting with the AAC Mentors was useful and I gained knowledge from them.

strongly agree agree neutral disagree strongly disagree not applicable

I would send my child to this camp in the future, if I had the opportunity.

strongly agree agree neutral disagree strongly disagree not applicable

I would recommend KiwiChat Camp to a friend whose child uses AAC.

strongly agree agree neutral disagree strongly disagree not applicable

Please use the space provided to answer the following questions:

1) What did your child (who uses a communication device) learn/gain from this camp?

.....
.....
.....

2) What did your other child/children learn/gain from this camp?

.....
.....
.....

3) What did you learn/gain from the camp?

.....
.....
.....

4) My goals/expectations for the camp were achieved? Please provide some comments below.

strongly agree agree neutral disagree strongly disagree not applicable

.....
.....
.....

5) Did you learn/gain anything from camp which you had not expected?

.....
.....
.....

6) What is your goal for using the communication device for when you go home?

.....
.....
.....

7) What parts of the camp did you find most useful?

.....
.....
.....

8) What parts of the camp did you find least useful?

.....
.....
.....

9) Is there anything else you would like to see included in future camps?

.....
.....
.....

10) Do you have any suggestions for changes to future camps?

.....
.....
.....

11) Please add any other comments

.....
.....
.....

Thank you for taking the time to complete this survey.

We understand that some of these questions may have caused an emotional reaction. If you feel in any way upset or concerned, please talk with a support person (e.g. your TalkLink Speech Language Therapist or a family member) the Camp Organiser (1234567) or the researcher (Jessamy Amm, 095571214, 0210444681).

Please remember that your anonymised responses will be shared with the Camp Organiser, to assist with planning and improvement of future camps.

Appendix J: Interview Questions for Parents

**INTERVIEW QUESTIONS FOR PARENTS OF CHILDREN WHO USE AAC**

What did you think of KiwiChat Camp?

Before coming to KiwiChat Camp, had you met other people who use a communication device to talk? If so, please tell me about your experiences.

Have you learnt more about using a communication device while you've been at KiwiChat Camp? What have you learnt?

Please tell me about your experience of having a child who uses a communication device to support their communication? What are the positives? What are the difficulties?

Could you describe your experience of networking with other families of children who use a communication device during KiwiChat Camp?

Could you describe your experience of meeting <insert Mentor's names> who use a communication device?

Do you feel that KiwiChat Camp has benefited your family? If so, in what way/s?

Has KiwiChat Camp met the goals and expectations you had before you came? If so, in what ways? Was there anything that surprised you while at Camp?

What are your thoughts on providing therapy and training in the camp format versus more traditional approaches, such as 1:1 training in your home or one-day workshops?

Do you feel more confident about supporting your child to use their communication device at home and around your community, like the shops or playground? What has helped you to feel more confident?

What will you tell your friends/family/colleagues about KiwiChat Camp when you get home?

If you got the chance, would you like to come to KiwiChat Camp again?

At the end of the interviews, the researcher will suggest that the parents talk with a support person (e.g. the teacher or Speech Language Therapist who attended camp with them) about the interview discussion, if they feel that the questions have caused any type of emotional reaction.

Appendix K: Post-camp survey for Children who use AAC

**POST-CAMP SURVEY FOR CHILDREN WHO USE AAC**

This project is being carried out by Jessamy Amm, a Masters student in the Speech-Language Therapy program at Massey University, Auckland, under the supervision of Dr Sally Clendon and Dr Elizabeth Doell.

The aim of this project is to explore the views and experiences of families attending the KiwiChat Camp for children who use augmentative and alternative communication (AAC). We know that children who use AAC require significant input in order to learn to use their AAC systems independently and spontaneously and there are many different methods of providing this teaching and support. There is very little understanding of how an intensive camp might benefit the AAC user and their family.

This survey aims to investigate the KiwiChat Camp experiences for children who use AAC.

If you have any questions relating to the project, please contact Jessamy Amm on 0210444681 or jessamy.amm.1@uni.massey.ac.nz. Alternatively, you can contact Dr Sally Clendon on 414 0800 Ext. 43537.

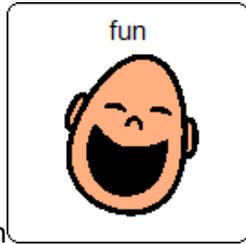
Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application MUHECN (#). If you have any concerns about the conduct of this research, please contact Dr Andrew Chrystall, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43404, email: humanethicsnorth@massey.ac.nz

Thank you for your participation in this project.

Name:

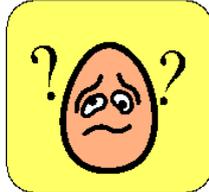
Please put a circle around the answer.



1) KiwiChat Camp was fun



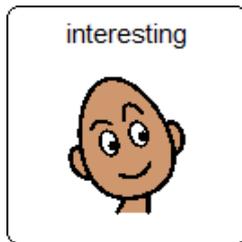
I agree



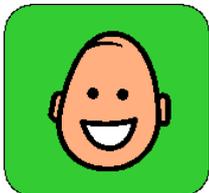
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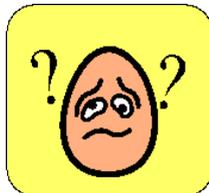
I disagree



2) The camp activities were interesting



I agree



I'm not sure



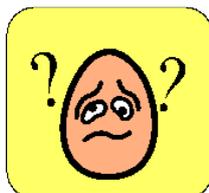
I disagree



3) I enjoyed the camp show



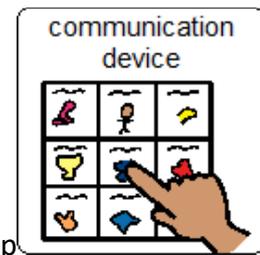
I agree



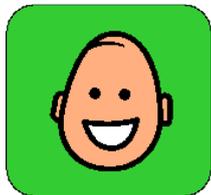
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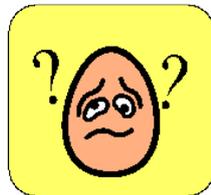
I disagree



4) I learnt a lot about using my communication device at KiwiChat Camp



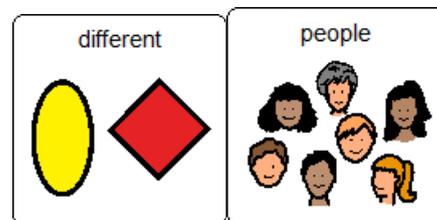
I agree



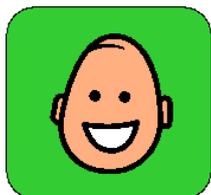
I'm not sure



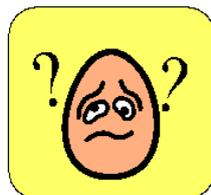
I disagree



5) I used my communication device to talk to a lot of different people at KiwiChat Camp



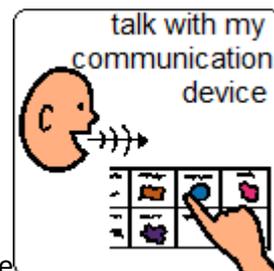
I agree



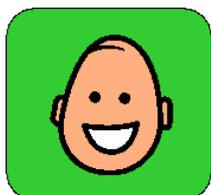
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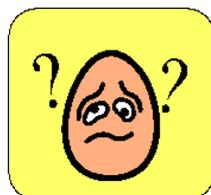
I disagree



6) I want to use my communication device when I go home



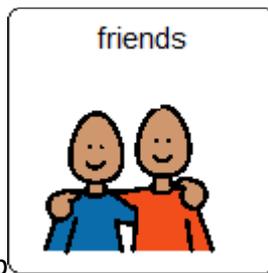
I agree



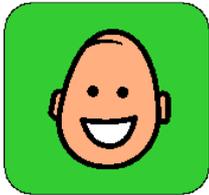
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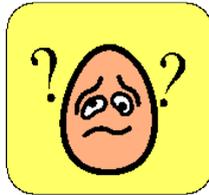
I disagree



7) I made friends at KiwiChat Camp



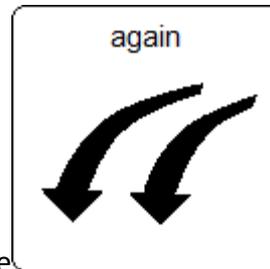
I agree



I'm not sure



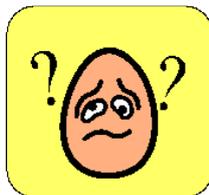
I disagree



8) I want to KiwiChat Camp again if I have the chance



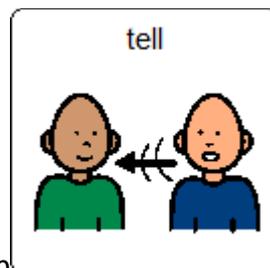
I agree



I'm not sure



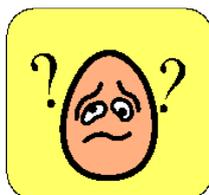
I disagree



9) I would tell my friends about KiwiChat Camp



I agree



I'm not sure



I disagree

10) Anything else you would like to tell us?



Thank you for completing this form

SLT Student Note

Please note how the camper you supported filled out the form:

- Independently
- Partner assisted scanning
- Verbal prompt
- Visual prompt
- Physical prompt
- Other – please explain

At the end of the survey, please suggest that the camper you completed this form with, talk with their parents or another support person (e.g. the teacher or Speech Language Therapist attending camp with them) about the survey questions.

Appendix L: Interview Questions for Siblings

**INTERVIEW QUESTIONS FOR SIBLINGS OF CHILDREN WHO USE AAC**

Children between the ages of 5-15 will be asked for their consent before the session starts. The following script will be used. Their parents will also sign a Consent form.

“Hi, my name is Jessamy. I am involved in a small research project and would like you to help me. I would like to find out what you thought of coming to KiwiChat Camp and what it’s like to have a brother or sister who uses a communication device. You can choose to leave the group at any time. Would you be happy to help me out? (if they give consent) Would it be ok if I use my phone to record our chat?”

Children 16 years and older will given the Older Children Information Sheet and Older Children Consent Form to sign.

What did you think of KiwiChat Camp?

What was your favourite part?

What was boring?

Before coming to KiwiChat Camp, had you met other people who use a communication device to talk?

Have you learnt more about using a communication device while you’ve been at KiwiChat Camp? What have you learnt?

What’s it like having a brother or sister who uses a communication device to help them talk?

What is good about it? What is difficult or tricky?

What was it like using the communication devices in the games this morning?

What was it like talking to other kids who have a brother or sister who uses a communication device?

What did you think of meeting the older people <insert names of mentors> who use communication devices?

Did camp help you to feel more confident about helping your brother or sister to use their communication device?

What will you tell your friends about KiwiChat Camp when you get home?

If you got the chance, would you like to come to KiwiChat Camp again?

At the end of the focus group interviews, the researcher will suggest that the children talk with their parents or another support person (e.g. the teacher or Speech Language Therapist attending camp with them) about the interview discussion.

Appendix M: Codebook: Siblings

Codebook: Siblings

Codes	Definition	Quotes
Enjoyment of camp in general	A feeling of happiness or pleasure caused by doing or experiencing something you like, expressed as 'fun'	<ul style="list-style-type: none"> • I love it! • It was really nice. • It was really cool. • Really fun.
Enjoyment of activities	Expressing happiness and pleasure in participating in certain activities or non-enjoyment, expressed as 'didn't like'	<ul style="list-style-type: none"> • I like all the activities. • That we umm had fun activities that we could do while our siblings and our mums and dads were doing things.
Connecting with others who use AAC	Enjoyment of experiencing a social relationship built on a shared common experience (attending KiwiChat Camp) and the feeling that you belong to a group and generally feel close to other people	<ul style="list-style-type: none"> • It's just cool meeting other people who are learning the same things that you are. • I liked actually sort of like when we weren't doing the activities like how the different siblings communicated with each other. That was cool to sort of see the different ways that people have been enabled to do that.
Connecting with mentors	Enjoyment of experiencing a social relationship built on a shared common experience (mentors giving knowledge, siblings and families receiving knowledge, feeling inspired)	<ul style="list-style-type: none"> • It was awesome! Actually, I bought the mentor something from the camp shop. • Cool. Because it was cool that she can use her Talker with her big toe.
Increased AAC use	The camp experience resulted in increased AAC use during camp	<ul style="list-style-type: none"> • My brother has been using it to communicate a lot more ... since being at camp.

Increased confidence	Feeling a belief in one's self and one's abilities to use AAC more and better than before coming to camp	<ul style="list-style-type: none"> • Yes, because like I said before it was a new and I feel a bit more confident in talking to her with it now. • I think I am a bit more confident in using it. I think I know a bit more than when I came here.
Increased motivation to learn	Feeling motivated (an external force that compels you to achieve goals and take action) and encouraged to participate in AAC training when offered	<ul style="list-style-type: none"> • [would you like some training?] [I'm seeing lots of nodding] • [Have you guys had any training before on how to use a device] [You are showing me a 'little bit']
Increased knowledge of AAC systems	Increased knowledge and awareness about navigation pathways on their sibling's AAC system, the range of AAC systems and access methods available	<ul style="list-style-type: none"> • Like if you don't know how to talk you can like use like push whatever button you want so that you can tell what you want or what to say. • The technology is great! • I've learnt lots of new pathways on the TouchChat.
Increased knowledge of how to be a good communication partner	Learning skills that will allow their sibling who uses AAC to develop their competency	<ul style="list-style-type: none"> • I guess sort of just using it in conversations. So like if she had a good day at school and stuff like that. • Well my sister like it was kinda new so I've learnt how to use it and kinda communicate with her.

Appendix N: Codebook: Parents

Code Book: Parents

Codes	Definition	Quotes
Motivating	Feeling motivated (an external force that compels you to achieve goals and take action) and encouraged to continue and increase AAC use and support in all contexts	<ul style="list-style-type: none"> • Motivation and belief in AAC is stronger than ever before. • Motivation to continue trying to get her to use it. • I definitely feel more confident/motivated to use the device with my child. • But it did motivate us to use it [AAC device] more. Yes, we use it every day now. • Well, it's not so much confident but more motivated. • I find it very difficult to motivate ... and he still doesn't get how it is helping him or how it could help him.
Inspiring	Feeling inspired (an internal driving force which gives you the vision to achieve your goals) to continue and increase AAC use and support in all contexts	<ul style="list-style-type: none"> • Mentor's experiences where inspiration and very valuable. • An emotional, mind-blowing experience to be able to have a future full of potential. • We were unaware of what people can achieve with AAC until we saw the role models talk to us. That left us speechless and was very inspiring. • It was absolutely mind-blowing, awesome and it gave me as a parent a new perspective about what M was capable of • R found the whole thing inspiring, profound and heartbreaking and uplifting and one of the most important aspect of the camp. • We had no idea that there was such a range of different possibilities and how amazing that is.
Empowering	Feeling empowered (being given power and authority) to act on new information about AAC and share it with others	<ul style="list-style-type: none"> • This was our first camp and I really had no expectations. However, now I feel more empowered as parent and realise I need to be more involved and not leave it to school. I feel any expectations may have been exceeded by the experience. Camp was very good. • So, I think that [saying something on his device that he cannot communicate verbally] has got to be really empowering for him and I think he gets that. It was mind-blowing!

Overwhelming	Feeling overwhelmed by the intensity of camp activities and large amount of information being learnt	<ul style="list-style-type: none"> • It is empowering for both parents and children and the ability to network and have such a variety of things going on [at camp]. • I was glad my son was here to help me. I didn't realise how difficult it would be at camp with J. Especially at mealtimes as she is such a slow eater. It would have been difficult to get to things on time if I was dealing with her on my own. • Only because I had younger children, sometimes the night time events were a bit tricky but they were great for older kids. • We both felt really shell-shocked after that first day. • I got really upset [at the mentor workshop]... So, I found her presentation really emotional • It was too rushed ... we had to go and run to the next thing and it was actually and for J that was all too much ... it was full on.
Technical skills	Learning technical skills specific to their child's AAC system	<ul style="list-style-type: none"> • Specific navigation usage of his device. • Learned some editing that is going to help a lot. • Gradually do some more programming. • I also learnt about the scenes and just navigating around the device, like learning about the action words and the describing words • The thing that I would have liked to do more of was editing
Aided language stimulation	Learning about aided language stimulation, it's importance and how to implement it practically into everyday life	<ul style="list-style-type: none"> • More knowledge of/confidence in modelling on core board, which I'll use more at home. • Gained knowledge about when and how to use AAC and model it for A. • Learnt how to use the core words boards more at home and for Sunday School. • I really took on board about modelling using the device so I will say 'let's see if we can find this together' 'what pathway will be need to take to get that word'. • It's modelling modelling modelling • It was really clear how quickly she gained skills by being immersed [in AAC and ALS].

General awareness of AAC	Learning that AAC is a continuum rather than a hierarchy and that all modes of communication are equally valid and practical	<ul style="list-style-type: none"> • Awareness that his AAC is as valid a communication tool as any other means of communicating. • So so much! Feeling the real benefits of using AAC including high tech, core boards, visuals and Makaton – a "tool belt" for communication. • There is no clearly defined path. Many different ways to "do" AAC but every person is very unique. We need to just do it, don't worry about what we are "supposed" to do. Also J's needs/system are likely to change over time. • Explored different AAC devices with aim of improving child's communication. "start where we aim to end" • The main thing I learnt more about was the core boards. I guess in the past I had seen them more as a level thing. At first you do this and then you abandon it because you are using your Talker. Like it's a progression or something.
Increased expectations	Feeling a strong belief that something will happen	<ul style="list-style-type: none"> • Modelling expectations based on what we know M's capabilities are – more use in everyday settings – feedback to school and with friends and family to raise their awareness and expectations of M. "Sorry M I couldn't understand – can you tell me on your Talkie?" (let's have everybody asking him this question) • Use it for one activity every day (getting ready etc) and change each week the word to focus on. Get my caregiver on board with how to model on the core board so she'll use it with my child too. Start using device at school. • To find 5 situations where we can consistently use/model the use of A's iPad for communicating simple sentences. • And it's not about a whole lot of time but it is just about an expectation. • It is not even about the children, it is about the adult's expectation.
Increased AAC use	The camp experience resulted in increased AAC use after camp	<ul style="list-style-type: none"> • She is asking to use it [PODD]. • I learnt that my boy is a rock star Talkie user and that the involvement of peers and teacher expectations lifted his level of engagement 100% - we couldn't get him to turn his Talkie off at mealtimes. • Certainly since KiwiChat Camp, M is using his device every day.

Increased confidence of child who uses AAC	Feeling that their child had a consciousness of their own skills and abilities in communication	<ul style="list-style-type: none"> • He is using whole sentences now rather than just using single words. • Yes, we use it [AAC system] every day now. • I think she has become more confident in using her PODD. • A gained confidence and enjoyment using AAC in the camp environment. • She gained confidence in using her AAC.
Increased confidence of family	Feeling that they had a consciousness of their skills and abilities in communication	<ul style="list-style-type: none"> • Vastly increased confidence in using the TouchChat app and strategies for using it "consistently" in everyday life and situations. • Our main goal was to become more confident users of AAC/TouchChat to be able to use it consistently with A and model its use for him. We feel we've taken big strides towards that in these 3 days. While it is hard to assess improvements in A's ability to use TouchChat no doubt we as a family have gained hugely from this experience.
Connection with other families	Social relationships built on a shared common experience (attending KiwiChat Camp) and the feeling that you belong to a group and generally feel close to other people	<ul style="list-style-type: none"> • Also was great to meet other parents dealing with similar issues. • Families - good connecting with others from our own area/and others and sharing ideas. • Connections with other families. • It was great because it makes you realise that you are not the only one with such complex needs but that we are actually pretty far-flung. • It was good having someone attend camp who was close to our area. • We just feel that it was so great meeting all the other kids. It was awesome because they are all so different in terms of complexity and severity and stuff but we all just has this one thing in common.
Connection with other children who use AAC	Social relationships built on a shared common experience (using AAC for communication)	<ul style="list-style-type: none"> • He made friends. • She saw everybody using AAC and that was the huge benefit. • Opportunity for my child to interact closely with other kids with disability.

Connection with mentors	Social relationships built on a shared common experience (mentors giving knowledge and encouragement to families and families receiving knowledge and feelings of inspiration)	<ul style="list-style-type: none"> • Mentors sharing their experiences, particularly of their childhood. • Expert talk on how to use AAC in everyday situations. • Having mentor and other mentors share their experience with AAC. • This was a personal first for both of us to be able to hold a conversation with somebody who was using a device for communicating and that was with M and G. • So, I'm assuming for all those kids who were there it would have been a really positive and empowering thing of having them there. • And I guess I also like that, because L, she has this sort of nature that she wants to do it herself and master it. Because she sees how well Mentor can communicate with her Talker and now she wants to do that.
Connection with staff	Social relationships built on a shared common experience (develop skills, knowledge and motivation for AAC implementation)	<ul style="list-style-type: none"> • The support both technical and emotional in terms of meeting other families and the amazing TalkLink team, students and volunteers. • Thanks also to the volunteers who looked after my other children. They all had a great rapport with them, wonderful people. • The involvement of SLT and OT students was an inspiring view to the future for assisted communication aspirations. • Everybody's enthusiasm and we know that you did huge hours to make that happen and it really was good for all of our souls and it is so good to have our children around people who are so enthusiastic about them.
Enjoyment	A feeling of happiness or pleasure caused by doing or experiencing something you like, expressed as 'fun', 'awesome', 'fantastic.'	<ul style="list-style-type: none"> • Lots of laughter, dancing and fun catching burglars. • A having a fantastic fun learning time. • We didn't know what to expect but was an awesome experience. • Thank you!! For all the hard work put into the camp. It ran smoothly and the kids had a magical time. • We would love to go every year. • I think that the kids that haven't had that opportunity yet are really missing out or that their families are really missing out.

Developing identity	Developing a sense of self and building a connection with others who are seen as similar, through their shared qualities, beliefs and experiences	<ul style="list-style-type: none"> • It was really good being at KiwiChat Camp and thinking about identity. • Like with meeting the other kids [mentors], you could see that little sense of identity that she got. • You could see that she was getting a bigger sense of her place in the world.
Sense of belonging	A feeling of closeness or affection from being united by a common state with other people	<ul style="list-style-type: none"> • A sense of "fitting in" with a group of people in a way that our family generally doesn't back in the "real world". • Child was in a place where he was "the same" - he belonged • That we are not alone in the struggles of having a child with a disability. • To feel part of a community and be able to allow my daughter to be a part of this! • You could see that others had the same struggles and we are all in the same boat and we are all trying and basically you are not alone. • The other aspect of networking was there was a sense of 'we are all in this together' even though we were with each other for a really minuet period of time of our whole lives.

Note. Blue quotes are from the surveys and black quotes is from the interviews.

Appendix O: Ethics Approval



7 April 2016

Jessamy Amm
12 Devana Court
Torbay
Auckland 0630

Dear Jessamy

**HUMAN ETHICS APPROVAL APPLICATION – NOR 16/04 KiwiChat
Camp: Experiences of Children with Complex Communication
Needs and their Family/Whanau**

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

A handwritten signature in black ink, appearing to be "A. Chrystall".

Dr Andrew Chrystall
Chair Human Ethics Committee: Northern

cc Dr Sally Clendon Senior Lecturer in Speech and Language Therapy Institute of Education

Te
Zealand

Kunenga Research Ethics Office ki Pūrehuroa Private Bag 102 904, Auckland, 0745, New
Telephone +64 9 414 0800 ex 43276 humanethicsnorth@massey.ac.nz

Appendix P: TalkLink Confidentiality Form



Speech Language Therapy Student / Volunteer Confidentiality Agreement

I, the undersigned, hereby agree not to divulge any information or records concerning any TalkLink client or other TalkLink business without proper authorisation from the TalkLink manager. I recognise that any discussion or release of information concerning TalkLink or a TalkLink client to any unauthorised person is forbidden and may be grounds for legal and/or disciplinary action.

During the performance of my assigned duties, I will have access to confidential information regarding TalkLink business and information required for effective client service coordination and delivery. I agree that all discussions, deliberations, records, and information generated or maintained in connection with these activities will not be disclosed to any unauthorised person.

I recognise that unauthorised release of confidential information may expose me to further action taken by involved parties and is in violation of the code of conduct set out by the New Zealand Speech Language Therapist Association (NZSTA).

Date:

Student Signature:

Name (Print):

Supervising Therapist:

Signature:

Date:

TalkLink Trust
Level 3, Cue Design House, 187 Willis St, Wellington
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