

ENVIRONMENTAL FACTORS
THAT INFLUENCE TELECOMMUNICATIONS USE BY
ADOLESCENTS WITH CEREBRAL PALSY

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“For I know the plans I have for you, declares the Lord,...plans to give you hope and a future.” Jeremiah 29:11

ABSTRACT

Background: Social participation is essential to well-being for adolescents with and without disabilities. Adolescents with a disability, however, often have fewer friendships and experience social isolation compared to their peers without disability. Telecommunications play a vital role in facilitating social participation for adolescents yet those with a disability experience reduced access. Based on the World Health Organisation's framework of the International Classification of Functioning, Disability and Health (ICF) this study aimed to identify environmental factors (barriers and facilitators) that impact on participation in telecommunication use, as perceived by adolescents with cerebral palsy and their communication partners.

Method: A qualitative research design was adopted using observations and in-depth interviews with five dyads of adolescents with cerebral palsy and significant communication partners. Data from interviews was analysed using qualitative content analysis to identify barriers and facilitators.

Results and Conclusions: A total of 66 facilitators and 72 barriers to telecommunication use were identified. These were divided into four categories; people-related, equipment-related, support/training-related and 'other'. A large number of interrelated people and equipment related factors were identified. Participants also identified the need for further training and support. In order to improve social participation for adolescents with disabilities, future research must investigate the development of assessment tools that accurately identify environmental barriers to telecommunication use and contribute to the development of strategies to overcome these barriers.

INTRODUCTION

Social participation refers to the process of taking part in social interactions and begins as early as parents making eye contact with newborns or the sharing of infants' first smile (Owens, 2005c). This develops rapidly to the sharing of sounds, words and, as time goes on, complex sentences and non-verbal subtleties (Owens, 2005a). This development of social participation can be examined from three different theoretical perspectives including; biological (Gray, 2002), cultural (Bronfenbrenner, 2005) and cognitive (Garhart, 2000). These perspectives are intertwined and point to the importance of social participation for well-being and quality of life.

Social participation is important for physical and mental health (Hawkey, et al., 2008; Reis, Wheeler, Spiegel, & Nezelek, 1985) yet many people report experiencing social isolation (Hawthorne, 2008). Adolescence is a period in which a supportive social network is of particular importance as it is a time of major social development (Turkstra, 2000). The development of social networks is central to well-being during this period as the influence and adolescents seek to develop an identity separate from family (Gray, 2002; Turkstra, 2000). Failure to develop effective social networks may lead to loneliness (Stokes, 1985), with adolescents more at risk of feeling lonely than any other population (Brage, Meredith, & Woodward 1993; Stokes, 1985).

Social participation is also essential to well-being for adolescents with disabilities (Berntsson, Berg, Brydolf, & Hellstrom, 2007; Wilson, Washington, Engel, Ciol, & Jensen, 2006) although they may experience this social participation differently (Stevens, et al., 1996). Adolescents with a disability may experience friendships that are less intimate and fewer social activities (Skar, 2003; Stevens, et al., 1996). In recent years, the use of telecommunications has been identified as an important tool in developing and nurturing

social networks (Lacohee, Wakeford, & Pearson, 2003; Wellman, 2001), particularly for young people (Harley, Winn, Pemberton, & Wilcox, 2007; Walsh, White, & Young, 2008).

Young people are at the forefront of telecommunication use with higher Internet and mobile phone use than the general population (Roberts & McFarlane, 2008). Use of telecommunications has become integral to social participation of adolescents today for several reasons; it facilitates social networks (Harley, et al., 2007; Internet Safety Group Inc, 2005), it reduces loneliness (Wei & Lo, 2006), and provides an increased sense of identity, particularly with a group (Carroll, Howard, Peck, & Murphy, 2002; Wei & Lo, 2006). It is clear that telecommunications contribute to a sense of identity as well as providing adolescents with a means of social participation. Less is known, however, about the use of telecommunications by people with disabilities, particularly amongst adolescents and how it relates to their social participation.

People with a disability are likely to use telecommunications less frequently than people without a disability (Bryen, Carey, & Friedman, 2007; Kaye, 2000). There are many who would advocate that access to telecommunications, by people with disabilities, needs to be addressed at a policy level (Goggin & Newall, 2007; Jaeger, 2006) and that without an accessible telecommunication system, a physical disability can become a social disability (Goggin & Newell, 2000).

In addition, people with a disability face significant barriers to accessing telecommunications; design of equipment poses physical restrictions (Smith-Jackson, Nussbaum, & Mooney, 2003; The Center for Universal Design, 2003), cost of special equipment or modifications is prohibitive, communication partners have a limited understanding of the person's communication style and there is a lack of specialised training and support (Carey, Friedman, & Bryen, 2005; Greig, Harper, Hirst, Howe, & Davidson,

2008; Mann, Belchior, Tomita, & Kemp, 2005). Yet, research has also shown that the matching of appropriate equipment and the provision of training can improve access to telecommunications, increase self esteem and quality of life (Bryen & Pecunas, 2004; Nguyen, Garrett, Downing, Walker, & Hobbs, 2007). Furthermore, recent developments in telecommunications, such as short message service (SMS) and electronic mail (email), has enabled many people with a disability to overcome communication barriers across the disability divide (Pilling & Barrett, 2008; Power & Power, 2004; Power, Power, & Horstmanshof, 2007).

To date, research about how adolescents with a disability use telecommunications is limited and little has been documented about the barriers and facilitators that impact on their telecommunication use. This information is vital if the disparity between disabled and non-disabled telecommunication use is to be addressed. Also, this information is essential in developing appropriate services aimed at reducing barriers and telecommunication use and as a result enabling greater social participation by all. One group that experiences reduced social participation as well as difficulties accessing telecommunications is adolescents with cerebral palsy (CP) (Blum, Resnick, Nelson, & St Germaine, 1991; Krakovsky, Huth, Lin, & Levin, 2007; Nguyen, et al., 2007). This study aims to examine the barriers and facilitators impacting on telecommunication use as perceived by adolescents with CP and their communication partners. These are considered within the framework of 'The International Classification of Functioning, Disability and Health' (ICF)(World Health Organisation, 2001).

Social Participation

As young children develop, their ability to participate socially becomes increasingly skilled and adopts more forms. Initially social participation takes the form of a joint focus, imitating expressions and sounds, communicating through simple words and body language

(Owens, 2005b). Subsequently, a child develops the ability to share words in order to engage socially. This gradually progresses with the acquisition of complex spoken and written language skills (Owens, 2005a). Therefore, communication is a tool for participating socially. The 'toolbox' is extended to include different modes of communication; namely, written (such as letters, emails, text messages), spoken and visual communication over distance (phone calls, video calling etc.). To examine the construct of social participation in more detail, a closer examination of the factors influencing social participation and its importance for human development is required.

In the case of social participation, the word 'social' is an adjective used to describe a way of participating. It can relate to society, interactions between individuals and groups, living in a community (as opposed to living alone) and to the nature of people's interactions ("Encarta® World English Dictionary," 2009, p. 10). On the other hand, 'participation' refers to the act of taking part, being 'part of the whole', the process of involvement, consultation and ownership (*New Oxford American Dictionary*, 2005). The Ministry of Social Development defines participation as, "opportunities both to contribute to neighbourhood, community and national life as well as influence decisions that affect us" (Bromell & Hyland, 2007, p. 10). Therefore, social participation can refer to the process of taking part in interactions, of a social nature, between individuals or groups, being part of the whole, or in other words being an active participant in one's community.

Historically, three theoretical perspectives exist regarding the development of social participation in humans; 1) biological (maturation of inborn social drives), 2) cultural (social adaptation to the norms and values of a person's culture), and 3) cognitive (social development as an outcome of general growth in intellectual ability) (Gray, 2002). One of the first to describe *biological* drives behind the development of social participation was Sigmund

Freud (Gray, 2002). His psychodynamic theory of personality focused on the role of universal human drives which influenced the way people interacted socially. According to Freud, sexual and aggressive drives were of particular importance and social development was a matter of learning how to channel these drives in socially acceptable ways. This occurred primarily in the first five to six years of life through a child's relationship with parents (Gray, 2002).

A leading theorist in *cultural* theory of the development of social participation was Bronfenbrenner (Bronfenbrenner, 2005; Gray, 2002). His *social ecology theory* refers to the entire network of social interactions and interdependencies in which a person must adapt and develop. These are depicted in a set of concentric circles with the child at the centre followed by; immediate environment (e.g. home and school), interrelation among immediate environments (e.g. a parent's attitude toward a school), social context (e.g. parent's place of work, the school board) and finally cultural context (the beliefs/values of the culture to which the child belongs). According to Bronfenbrenner, a person's ability to participate socially develops within a system of multiple layers of social influences which form a person's unique cultural context (Bronfenbrenner, 2005).

Cognitive theories generally describe social behaviour as a reflection of cognitive development (Gray, 2002) with Jean Piaget the major contributor (Garhart, 2000). Piaget stated that cognitive development results from the child's actions on the environment resulting in an internal representation of how the environment works. The way a child perceives their physical world influences how they perceive their social world. For example, as a child develops the cognitive ability to understand cause-effect relationships in the physical environment, they are also able to understand cause-effect aspects of social relationships (Garhart, 2000).

In summary, theories regarding social participation and its development have highlighted three important aspects. Firstly, social participation is an universal biological phenomenon crucial to survival from infant onwards, secondly, social participation occurs within a person's unique cultural context with its varying circles of social influences and thirdly, social participation is influenced by our ability to make sense of our world cognitively. It could be suggested that these three perspectives on social participation are in fact intertwined, with each forming part of the whole. There is a need for further consideration of the importance of this multi-faceted social participation as it relates to well-being and quality of life.

The Importance of Social Participation

Social participation is important for health and well-being (Hawkey, et al., 2008; Reis, et al., 1985) yet people commonly report perceived social isolation (Hawthorne, 2008). Hawthorne (2008), in a random sample of Australian adults ($n=3,015$) reported that up to 16% of participants experienced some social isolation as measured via self-report. Furthermore, the study reported a strong association between depression and perceived social isolation. Social participation, or the lack thereof, is not only relatively common but can result in increased loneliness, poor health, and increased risk of depression.

Social participation has been found to exhibit a significant effect on health. Reis et al. (1985) examined the effect of social participation and the physical and psychological health of 98 university students. Social interactions were measured by participants keeping daily records of all interactions, involving joint attention and behavioural responses, that were ten minutes or longer in duration. Health problems were measured by the number of visits to the Health Centre for various categories of illnesses. Health problems of a psychosocial/personal nature were described as any health disorder associated with stress or psychosocial

dissatisfaction, such as mental health problems or nervous system disorders (e.g. high blood pressure, asthma, headaches and malaise). Poor quality social interactions were measured by self reports of feeling less pleasure, satisfaction or intimacy with same or other sex interactions. Findings of the study indicated that, particularly for females, poor quality social interactions were associated with a higher incidence of health problems of a psycho-social/personal nature. General findings in the study supported the notion that social participation, and in particular the quality of that participation, has an impact on health.

Having a large supportive social network and having quality relationships have also been reported to reduce the risk of loneliness (Hawkley, et al., 2008). Loneliness has been described as follows:

“an enduring condition of emotional distress that arises when a person feels estranged from, misunderstood or rejected by others and/or lacks appropriate social partners for desired activities, particularly activities that provide a sense of social integration and opportunities for emotional intimacy.” (Rook, 1984, p. 1391)

Hawkley et al. (2008) examined the relationship between perceptions of relationship quality and loneliness in a population-based sample of 225 Americans aged between 50 and 68 years. Relationship quality was measured by a number of indicators including; self ratings of enjoyment and satisfaction with members of a person’s social network, having a supportive confidant and social network size. Social network size was defined as the total number of social contacts in three categories; confidants, people who caused them stress and those whom they had found to be supportive in the past year. The Revised UCLA Loneliness Scale (Russell, Peplau, & Ferguson, 1978), a 20-item validated measure of self-reported feelings of loneliness and social isolation, was used to measure loneliness. Results of the study indicated that participants with a smaller social network and poor-quality social relationships were more at risk of experiencing loneliness (Hawkley, et al., 2008).

The link between social participation and loneliness is clearly important as prior research has indicated that loneliness can may be related to increased blood pressure (Hawkley, Masi, Berry, & Cacioppo, 2006), suicidal thoughts (Brown & Day, 2008), and even faster ageing and physiological decline (Hawkley & Cacioppo, 2007). There are further factors that contribute to a person's ability to participate socially. Some of these factors include culture, health conditions and age, and are examined more closely in the following section.

Factors Influencing Social Participation

Culture

One factor that influences social participation is cultural influences. Bronfenbrenner refers to a person developing social participation skills within their unique cultural context (Bronfenbrenner, 2005). He describes the different subsystems, ranging from micro to macro, that form the ecological system in which a person develops. Cultural beliefs, customs and lifestyles form the overarching macro-system in this model (Bronfenbrenner, 1994).

In New Zealand the population has become increasingly diverse with many different ethnicities and cultures represented (Bromell & Hyland, 2007). The characteristics of social participation may present differently in each of these diverse cultures. For example, national survey data from 2001 indicated that Māori families were more likely to take part in family activities than those from 'other' ethnicities (i.e. other than Māori, Pacific peoples and European/Pakeha) who had the lowest levels of participation in family activities (Statistics New Zealand). This could suggest that within Māori culture there is increased social participation within a family setting. It does not necessarily mean that those of 'other' ethnicities experience less social participation. It may be that for those groups, families live further away (e.g. overseas) and that social participation takes place in another context.

However, it could suggest that culture does influence the way social participation is given expression.

Long term health problems

Levels of social participation are thought to be negatively affected by long-term illness or care for others (Platt, 2006). A review of the British Home Office citizenship Survey 2001 examined risks of reduced social participation in people who had, or cared for those with, long-term limiting health problems. Social participation was measured by survey questions relating to a person's social activities such as going on visits and being visited. Findings indicated that participants were at increased risk of reduced social participation indicating that social participation is impacted by either experiencing, or caring for someone with, a limiting long-term health problem.

Age

Social participation is known to vary across the lifespan (Balandin, Berg, & Waller, 2006; Brage, et al., 1993; Bukov, Maas, & Lampert, 2002; Hawthorne, 2008). Hawthorne (2008) examined data from 3,015 participants (15-60 years and over) taking part in a regional health survey in Australia, to examine the prevalence of social isolation. Perceptions of social isolation were found to be significantly more prevalent amongst 15-30 year olds than those aged 31 years and older. Specifically, nearly 22 percent of 15-30 year olds reported feelings of isolation, ranging from 'some isolation' to 'very isolated' on a 6-point self-report scale. This figure was higher than any of the other age groups indicating that younger adults, in particular, may experience feelings of being alone, separate to others and experience difficulties getting in touch with others (Hawthorne, 2008). Therefore, it could be suggested that addressing the issue of social participation is of particular significance in this life stage.

It is clear that adolescence is a significant life stage for the development of social participation. Given that adolescence forms the bridge between childhood and adulthood and is characterised by significant social development this is perhaps unsurprising. Adolescents exhibit growing independence from parental influences with the role of peers becoming more influential and the establishment of an autonomous identity within social networks and wider society (Turkstra, 2000). A closer examination of this developmental stage is necessary in order to understand more fully the significance of social participation in adolescence.

Adolescence

Adolescence forms the transition from childhood to adulthood. The onset of adolescence is signalled by signs of the onset of puberty (Gray, 2002). These physical changes associated with puberty begin between the ages of 10-12 years, with girls developing earlier than boys (Smith, 2005). It is a time of not only rapid physical but also psychological change with the maturation of the central nervous system taking place in this period. The conclusion of this adolescence is less clear. The finishing point may be signalled by the completion of physiological changes at around 20 years old or it may be signalled by the acceptance by self and others into adulthood (Smith, 2005). The latter may be largely culturally determined, with the entrance into adulthood being typified by the beginning of a career or/and a family within a western culture. Irrespective of exact time frames this period can be loosely divided into three stages (Gray, 2002).

Turkstra (2000) identifies three stages in adolescence; 1) pre-adolescence (9-12 years), 2) early adolescence (13-16 years) and 3) late adolescence or early adulthood (17-21 years). Early adolescence is characterised by rapid physical development, including the development of sexual characteristics (Gray, 2002). Physical appearance becomes a focus and a way of identifying oneself with a group (Turkstra, 2000). Early adolescents also spend about one-

tenth of their time talking, either on the phone or in person (Turkstra, 2000), with girls spending twice as much time talking as boys (Raffaelli & Duckett, 1989). It is a time in which there is a shift to loose-knit, mixed-sex social groups as well as increased intimacy in personal friendships (Turkstra, 2000).

Late adolescence (17-21 years), or young adulthood, is characterised by the transition into adulthood. This includes a need to develop skills for independent living and establishment of a personal identity independent of parents (Turkstra, 2000). Establishing an independent identity is something that develops throughout adolescence. According to Erikson's life-span theory, adolescence is described as the stage of identity crisis (Garhart, 2000). It is a time to shed one's childhood identity and establish a new 'adult' identity. Influences on how this identity develops shift from being strongly influenced by parents to looking increasingly to peers for clues on social behaviour (Gray, 2002).

Personal morals and values continue to develop and there are high expectations for self-regulation (Gray, 2002; Turkstra, 2000). Adolescence is a period in which social participation, particularly with peers and increasingly with those of the opposite sex becomes increasingly important (Turkstra, 2000). Peers form an important social network (Smith, 2005) and adolescents begin to spend more time in conversation with their peers than their family (Larson & McKinley, 1998). Therefore, it is important to consider the significance of social participation in adolescence.

Social Participation in Adolescence

The establishment and maintenance of social networks is central to well-being during adolescent development (Turkstra, 2000). Failure to develop effective social networks may lead to intense feelings of isolation (Stokes, 1985), with adolescents more at risk of feeling lonely than any other section of the population (Brage, et al., 1993; Stokes, 1985). Stokes

(1985), in a study of 179 college students, examined the relationship between social networks and loneliness. Social networks were measured by means of self-report using the 'Social Network List' (Hirsch, 1980) which indicated ; a) size of network , b) number of people the participant would confide in, c) percentage of network members that were family members and d) density of the network (interconnections between network members). Loneliness was measured with the UCLA Loneliness scale (Russell, et al., 1978). The study reported that participants with denser social networks (i.e. networks in which participants are interconnected and important in each other's lives) were less likely to feel lonely.

The link between social participation and loneliness in adolescents is an important one because of the impact loneliness can have on well-being. There appears to be a strong connection between feelings of loneliness, depression and self-esteem (Brage, et al., 1993). Brage et al. (1993) examined correlates of loneliness in 156 adolescents aged 11-18 years. A variety of tools, incorporated into a questionnaire, were used to measure loneliness, depression, self-esteem, family strengths, and parent-adolescent communication. Adolescents were reported to have high levels of loneliness. Furthermore, loneliness was significantly related to depression and inversely related to self esteem (Brage, et al., 1993).

Adolescents with supportive networks have been reported to be less lonely than adolescents without such networks (Stokes, 1985). It would appear that a sense of 'belonging' to a social network is critical to wellbeing in adolescence. Noam (1999) labelled this sense of belonging in Eriksonian terms of life stages as being the 'belonging-versus-rejection' stage. Some of the significant ingredients in this life stage include; a sense of self being strongly defined by the group and others, and a sense of belonging as being essential to well-being (Garhart, 2000).The following section will examine whether these same ingredients for experiencing well-being exist in adolescents with a disability.

Adolescents with a Disability

Adolescents with a disability have a wide range of impairments; physical, intellectual, mental and sensory (visual and hearing impairments) (Ministry of Health, 2004). Exact prevalence figures for disability in New Zealand are not available as data is commonly collected via specific disability subtypes as opposed to all disabilities. However, in New Zealand it is estimated that one in five people live with a long-term impairment (Ministry of Health, 2001). In 2001, 716,500 people with a disability lived in private households with 19% of these below the age of 25 years old. On that basis, it is clear that adolescents are likely to form a significant portion of the overall population of people with a disability. Therefore, closer examination of how adolescents with a disability experience social participation is fitting.

Social Participation in Adolescents with a Disability

Social participation has been found to be essential to well-being for adolescents with disabilities. Berntsson, Berg, Brydolf, and Hellstrom (2007) examined experiences of well-being in fifteen adolescents aged 12-19 years with a long-term illness or disability. Three primary themes positively associated with feelings of well-being emerged from a series of interviews conducted over a 2 year period. These themes were: 1) a feeling of acceptance of disability as part of life; 2) having a feeling of personal growth; and, 3) feeling supported by others. The latter is an indicator that participation in supportive social networks is critical to wellbeing.

Similarly, social supports, particularly those provided by families, appear to play a significant role in psychological adjustment and functional ability for youth with a physical disability (Wilson, et al., 2006). Wilson et al. investigated the relationship between these factors in 70 young people aged eight to 20 years. Perceived social support was investigated by

participants responding to eight items using a 7-point likert scale, related to perceived support from family and friends. Psychological adjustment was measured using a 16-item mental health scale requiring participants to rate different moods and feelings in the past four weeks. Results indicated that higher perceived social support, particularly from family, predicted better psychological adjustment. Participation by young people, in supportive social networks, including immediate family, appears to be closely associated with feelings of happiness and calm (Wilson, et al., 2006). However, not all young people with a disability are likely to experience these feelings of wellbeing.

Research has indicated that adolescents with disability are more likely to experience loneliness and associated distress than their peers without disabilities (Svetaz, Ireland, & Blum, 2000). Svetaz et al. (2000) analysed a cross-section of data from a national longitudinal study in adolescent health of 20,780 individuals. Just under 5% of adolescents ($n=1,301$) were identified as having a learning disability. Of these, 25% of males and 33% of females with learning disabilities reported experiencing severe emotional distress, a rate two to three times higher than that of the general adolescent population. Emotional distress was measured using a 17-item self report scale. The researchers identified a sense of connection to parents and school as factors contributing to lower levels of emotional distress. A sense of belonging and feeling connected to supportive social networks, such as parents and school, was reported as fundamental to emotional wellbeing in adolescents with a learning disability.

Interestingly, adolescents with a disability may experience social participation differently to their typically developing peers (Stevens, et al., 1996). Stevens et al. (1996) examined psychosocial aspects of health related to growing up with a physical disability. Survey results from 101 young people (11-16 years) with physical disabilities were compared with those from a Canadian national sample of typically developing adolescents. Findings

revealed that although adolescents with a disability reported having similar numbers of friends to their peers, friendships were less intimate and they participated in fewer social activities. Similarly, Skar et al. (2003) reported that adolescents with a disability had flawed or non-existent friendships with their non-disabled peers in an interview-based study of 12 adolescents aged 15 to 19 years. Furthermore, these limitations in social participation appear to persist later in life with older people (aged 40 and over) with cerebral palsy (CP) experiencing more loneliness than older adults without a disability (Balandin, et al., 2006). Given that loneliness is likely to persist there is a need to identify the barriers to social participation in adolescents with a disability.

Social participation for adolescents with a disability may also differ from their typically developing peers as a result of their perceptions of social networks (Matheson, Olsen, & Weisner, 2007). Matheson et al. (2007) examined perceptions of friendships among 27 young people aged 16 and 17 years with developmental disabilities and compared these findings with a group of typically developing peers. The conceptions of friendships, among adolescents with a disability, focussed on companionship, engagement in activities and long-term availability similar to their peers without disabilities. Proximity of others, such as being in a group or class together, were also identified by adolescents with a disability as a form of friendship. These are not typically associated with the notion of friendship. Interestingly, friendships with peers who have disabilities were also found to be more stable and positive than friendships with typically developing peers (Matheson, et al., 2007). Although perceptions of and the nature of social participation may vary amongst adolescents with a disability, it is clear that a sense of social connectedness is fundamental to well-being in both groups. Therefore, it is essential to investigate the influences that facilitate social participation. In recent years, the use of telecommunications has been identified as an important mechanism in developing and nurturing social networks.

Telecommunications and Social Participation

Telecommunication has been defined as; “the transmission of encoded sound, pictures, or data over significant distances, using radio signals or electrical or optical lines”(“Encarta® World English Dictionary,” 2009). The word ‘telecommunication’ is a compound of the Greek prefix ‘tele’, meaning ‘far off’ and the Latin ‘communicare’ meaning ‘to share’ (*New Oxford American Dictionary*, 2005). Therefore, telecommunications can be seen as a tool to share communication over distance. Telecommunications now include; traditional landlines, mobile phones, email, chat groups via the internet, Voice over Internet Protocols (VoIP) such as SkypeTM and specialised relay services.

Use of information and communication technologies (ICT), including telecommunications, has become an essential tool in social participation for many people (Lacohee, et al., 2003; Wellman, 2001). Lacohee et al. (2003) described the social history of the mobile phone. They report that although mobile phones (car phones) were being developed already in the mid 1950’s, it was not until the early 1990’s, with the development of digital networks and an increase in service providers, that the number of subscribers rose considerably. The initial development of mobile phones was as an elitist device for business and upper class males (Lacohee, et al., 2003). However, it has since been adopted for widespread social purposes with mobile phone use becoming an integral part of daily life.

Lacohee et al. (2003) further suggested that a correlation existed between changes in social participation and increased mobile phone use. Previously, traditional social networks could be described as hierarchical in nature. These have now become more horizontal in nature in the last few decades. The mobile phone has impacted, and was impacted by, new forms of social networking (Lacohee, et al., 2003). In addition, the world is increasingly complex with globalisation, ease of long-distance travel and geographical dispersion of

populations. There is a need to maintain a large portion of our social networks over distance which telecommunications enable us to do (Lacohee, et al., 2003). Therefore, telecommunications help shape and are shaped by the way we interact socially.

Telecommunications via the computer, including email and VoIP, have also become an integral part of modern social participation. Wellman (2003) in his historical review described computer networks as being inherently social networks. Previously, computers stood alone, appropriately labelled as 'personal computers'. With the development of electronic mail (email) in the 1980's and further development of the internet in the 1990's the worldwide web has become the largest and most fully connected social network of all (Wellman, 2001). The widespread influence of modern forms of telecommunication on social participation and networks is reflected in the phenomenal growth in phone subscribers.

According to the International Telecommunication Union (ITU), the United Nations agency for ICT, approximately 68% of people worldwide are telephone subscribers (International Telecommunication Union, 2008b). By late 2008 the ITU anticipated that four billion people worldwide will be mobile phone subscribers (International Telecommunication Union, 2008c). The rapid and widespread growth of mobile phone use in the last two decades has been phenomenal. Currently, researchers estimate there are more mobile phone subscribers worldwide than fixed line users (Davie, Panting, & Charlton, 2004). In New Zealand, 37% of households had access to the internet with 96% having access to a telephone (Statistics New Zealand, 2001). These data indicate that telecommunications have become a common means for social participation.

Globally, young people are at the forefront of telecommunication use. Internet and mobile phone use by young people (five to 24 years) is higher than the general population with peak use occurring between 15 and 24 years (Roberts & McFarlane, 2008). For example,

around 90% of young people between 15 and 24 years in the United Kingdom and Australia own a mobile phone (Harley, et al., 2007; Walsh, et al., 2008). Households with occupants between the ages of 10-19 years were most likely to have internet access (Statistics New Zealand, 2001). This widespread use of telecommunication by adolescents suggests that the use of the phone and the internet is fundamental to how adolescents maintain their social networks today.

Telecommunications Use by Adolescents for Social Participation

Research has demonstrated that telecommunication use by adolescents is important for social participation. The following reasons have been identified as contributing factors: telecommunication use facilitates social networks (Harley, et al., 2007; Internet Safety Group Inc, 2005), it reduces loneliness (Wei & Lo, 2006), and it provides an increased sense of identity (particularly with a group) (Carroll, et al., 2002; Wei & Lo, 2006).

Mobile phone use appears to be particularly important for adolescents to maintain peer-based social networks (Taylor & Harper, 2001). Taylor and Harper (2001) gathered ethnographic data through interviews with 120 participants aged 11 to 18 years. Analysis of the data revealed that mobile phone use promoted a sense of community, and allowed adolescents to demonstrate their involvement in a social network. In a survey of 909 Taiwanese college students (18-25 years), 96% were mobile phone users and the mobile phone was reported to be an important facilitator of social relationships (Wei & Lo, 2006).

New Zealand students also identified (mobile) phone use as playing an important role in maintaining social relationships (Internet Safety Group Inc, 2005). In a study involving 1,528 metropolitan high school students (12 to 19 years), 73% were identified as mobile phone users with 24% of these using two or more phones. The primary reasons for mobile phone use amongst the students were 'to talk and text with friends' (56%). Similarly, a study

examining mobile phone use amongst university students revealed that mobile phones were predominantly used to maintain social networks (Harley, et al., 2007).

A number of studies have found that the sending of text messages has become the predominant and preferred method of communication amongst peer groups (Harley, et al., 2007; Taylor & Harper, 2001) Adolescents have described learning the unique language of text messaging as a way of gaining membership into the group (Taylor & Harper, 2001). In Harley et al.'s study (2007) text messaging or short message service (SMS) was found to be the main form of electronic communication of university students.

Students who are late or infrequent users of mobile phones are likely to be less socially connected. Wei and Lo (2006) investigated the social connectedness of students in terms of loneliness and shyness. Loneliness was measured using the Revised USCLA loneliness scale (Russell, Peplau, & Cutrona, 1980) while shyness was measured on a 9-item scale of self-reported shyness. Those participants rated as 'lonely' were less frequent users of the mobile and did not use it for social purposes; rather they used it for its value as a status and fashion symbol. Participants in Wei and Lo's study (2006) reported making social gains by using mobile phones as a marker of fashion and status. This is consistent with Turkstra's (2000) report of the importance of physical appearance and social identity among adolescents. Carroll et al. (2002) examined mobile phone acquisition and use in a group of 34 adolescents (16 to 22 years). Motivational factors identified in obtaining and using mobile phones included an appealing style as a reinforcement of their identification with a group. Adolescents use their mobile phones as a way of consolidating their relationships with peers and differentiating themselves from their families. This is in keeping with this developmental stage in which gaining a sense of identity and increasing independence from family is important (Gray, 2002)

Research has demonstrated the importance of telecommunications to developing social relationships among young people. It is clear that telecommunications contribute to a sense of identity as well as providing adolescents with a means of social participation. However, less is known about the use of telecommunications by people with disabilities, particularly amongst adolescents and how it relates to their social participation. In order to do this it is important to look more broadly at how policy formation can influence telecommunication use and consider issues facing the disability sector as a whole.

Telecommunications Use by People with a Disability: Policies

During the World Summit on the Information Society (WSIS) , governments and world leaders committed themselves to building an information society that was people centred, inclusive and development-orientated where everyone can access and share information (International Telecommunication Union, 2008a). Telecommunications play an integral part in accessing and sharing information. Making telecommunications more inclusive to people with a disability is also in accordance with obligations under Article 9 of the United Nations' Convention on the Rights of Persons with Disabilities (United Nations, 2006). The Convention aims to promote and protect the rights and dignity of people with a disability. It recognises the inherent dignity, worth and equal rights of all people as part of the human family and seeks to redress the social disadvantage of people with a disability and promote full participation in all spheres of life (United Nations, 2006).

The adoption of inclusive policies around ICT services, including telecommunications use, constitutes a major facilitator at an international and political level. These policies also dictate that equal access be facilitated by the inclusion of persons with a disability in policy formation and design development in the early stages. This is crucial to ensuring systems become accessible at minimum cost (United Nations, 2006). Where this consultation has not

happened in the past, communication technology has not always been accessible, leaving people with disabilities excluded from their use unless costly assistive technology is developed and purchased (Goggin & Newell, 2000; Jaeger, 2006).

A number of researchers have advocated that access to telecommunications, by people with disabilities, need to be addressed at a policy level (Goggin & Newell, 2007; Jaeger, 2006) and that without an accessible telecommunication system, a physical disability can become a social disability (Goggin & Newell, 2000). They are of the opinion that unless access issues are addressed at the design stage and at policy level, ICT remains inherently inaccessible and socially isolating for people with a disability. Finally, the UN Convention states that valuing and facilitating full participation, including community participation via telecommunications, will not only result in an enhanced sense of belonging for the individual with a disability but will also lead to significant advances in the development of society as a whole (United Nations, 2006).

The New Zealand Disability Strategy (Ministry of Health, 2001), a policy document, has the potential to shape factors that will enhance or hinder the use of telecommunications by people with a disability. This document sets out a framework to guide Government action to promoting a more inclusive society in New Zealand. It aims to reduce barriers to participation in the community for the one in five New Zealanders who live with a long-term impairment.

Factors that Influence Telecommunication Use by People with a Disability

Research demonstrates that people with a disability are likely to use telecommunications less frequently than people without disabilities (Bryen, et al., 2007; Canadian Council on Social Development, 2002; Kaye, 2000) and that barriers prevent effective use (Bryen, et al., 2007; Bryen & Pecunas, 2004; Carey, et al., 2005; Greig, et al., 2008; Mann, et al., 2005). Research focussed solely on telecommunication use by adolescents

with a disability is limited, as studies often investigate telecommunication use according to type of impairment and across all ages. Therefore, it is necessary to consider factors influencing telecommunication use in the disability sector generally and across all age ranges.

Access to Telecommunications

People with disabilities are disadvantaged as they experience reduced access to telecommunication technology and services compared to people without disabilities (Bryen et al., 2007). Kaye (2000) examined computer and internet use among people with a disability. Findings indicated that people with disabilities are less likely to have a computer in their home; 23.9 % compared to 51.7% of Americans without a disability. Use of the internet by those with a disability is reported at only 10% compared to 38.1% of individuals without a disability (Kaye, 2000). Similar figures were noted in Canada with 56.2% of persons over 15 years using a mobile phone compared to only 36.6% of persons with a disability (Canadian Council on Social Development, 2002).

The recent formation of international policies is aimed at reducing these disparities in telecommunication use between those with or without disabilities (International Telecommunication Union, 2008b; United Nations, 2006). Bryen et al. (2007) examined the extent and scope of mobile phone use in 83 adults with intellectual disabilities and found that only 27.7% used mobile phones on a regular basis, compared to nearly 60% of the general population. Additionally, only 35% of participants with an intellectual disability used their mobile phones daily and 40% required help with use of the technology (40%). Participants were 18 years and older, with 45% of participants aged between 18-35 years of age. However, as the data was analysed collectively, no definite conclusions can be drawn specifically about how adolescents with a disability used telecommunications.

People with an intellectual disability access the telephone regularly but access to the internet is more limited. Carey et al. (2005) examined the use of electronic technologies (computers, phone, cell phones, internet, and electronic organisers) in 83 adults with an intellectual disability with ages ranging from 18 to 51 years and over. Nearly 90% reported using the phone regularly. A large majority (66%) reported having used a computer at some time in their lives yet only 44% reported using it on a daily basis with 25% using the computer several times a month or less. A further limitation was that 64% of those using a computer required regular assistance. 38% of those using a computer used the internet. However, the primary use of the internet was for games and information seeking. This indicates that limitations exist for people with a disability in utilising the internet for social purposes.

People experiencing visual impairments are also known to experience difficulties accessing telecommunications. Kelly and Smith (2008) compared the use of email and internet chat rooms by a group of adolescents (13 to 16 years) with visual impairments to findings from a national survey of typically developing adolescents. Only 38% of students with visual impairment used emails or chat rooms at least once a week. This was in stark contrast with typically developing adolescents (12-18 year olds) reporting an average of 53 minutes per day on the phone, 9 minutes per day using the internet (email, chat rooms) and 17 minutes per day Instant Messaging. Adolescents with a visual impairment also received significantly fewer telephone calls from friends than adolescents in other disability groups (e.g., intellectual disability). Consequently, adolescents with visual impairment are at risk of becoming socially isolated (Kelly & Smith, 2008). The authors commented that this finding is regrettable given the current capabilities of assistive technology to enable access to digital communication.

Access for People Using Augmentative and Alternative Communication

Another group within the disability sector who experience specific barriers to telecommunication use are those who rely on augmentative alternative communication (AAC) to communicate, whether lite-tech (manual signing, communication boards and books) or high-tech (speech generating devices or SGD). Specific needs exist with regards to the use of telecommunications by people who use AAC. Bryen and Pecunas (2004) described the experiences of an adult AAC-user, with a physical impairment, searching for an off-the-shelf solution for an accessible mobile phone. A creative solution was reported. This included mounting a mobile phone, speaker and microphone, to the wheelchair and attaching it to the wheelchair battery. However, the journey to find the solution took considerable time and effort on the part of the participant as well as the store technician.

Access to communication technology is essential for adults using AAC to develop and maintain social networks. Bryen, Potts and Carey (2006) examined the role of ICT in the maintenance of job-related social networks in a group of 38 adult AAC-users, aged between 19-59 years ($M=32.5$). Participants were found to use the internet, email and mobile phones to establish and maintain social networks. Participants also reported increased access to information and decreased social isolation through the use of technology.

People with a physical impairment have identified barriers that restrict or limit the use of SGDs (Murphy, Markova, Collins, & Moodie, 1996). These barriers impact on the person's ability to communicate, use telecommunications and participate socially. Murphy, Markova, Collins and Moodie (1996) undertook a two-year study of 93 adolescents and adults with CP and 186 communication partners examining contributing factors to the lack of use of SGD's. Factors identified included; a) limited availability and access to AAC systems, b) communication partners' limited knowledge of AAC systems, c) inadequate amount of

therapy and/or training, d) selection of vocabulary in AAC systems and other forms of communication available to the AAC user. These findings are significant because limitations which impact on device use will impact on a person's ability to use telecommunications (via their device).

Design

Application of the principles of Universal Design to the design of mobile phones is likely to reduce barriers to mobile phone use for people with a physical impairment (Leung, Joanna, & Sandhu, 2008; Smith-Jackson, et al., 2003). Universal Design involves technicians and designers considering accessibility issues from the outset of projects, striving for broad spectrum solutions that will support all people, with or without a disability (The Center for Universal Design, 2003). For example, larger buttons on a keypad would benefit many people with a disability but also the growing elderly population who use mobile phones. Bryen and Pecunas (2006) highlighted the need for Universal Design when considering 'off-the-shelf' solutions for mobile phone use for people with a physical impairment.

Access to Equipment

Mobile phone technology can have a significant impact on the lives of people with a physical disability (Nguyen, et al., 2007). Nguyen et al. (2007) identified 10 people with a range of physical impairments (e.g. cerebral palsy and muscular dystrophy) for participation in an in-depth study to examine the effect of mobile phone technology. The research involved a comprehensive assessment for suitability and provision of appropriate mobile phones. Participants were then matched with suitable 'off-the-shelf' technology and trialed the equipment. Comprehensive training and support were provided during the study. After a period of use, participant performance and satisfaction were measured.

Nine of the ten participants perceived their performance and satisfaction increased significantly with the use of the equipment provided. These increased levels of performance and satisfaction could be attributed to the level of support and training given. Nonetheless, the findings clearly show that people with disabilities can benefit from mobile phone use. The authors reported that improved access to telecommunications not only increased people's ability to communicate more effectively in their environment, but improved independence, self esteem and enhanced personal safety and security (Nguyen, et al., 2007). However, limitations exist in generalising findings from this study specifically to adolescents with a physical impairment. Although five of the 10 participants were 18 or younger, the authors did not make specific reference to how improved access to telecommunications affects adolescents with a physical impairment.

The barriers that people with a physical impairment may experience when attempting to access and use telecommunications was further highlighted by Mann et al. (2005). This study of 609 older adults with chronic health conditions, including various disabilities (visual impairment, learning difficulty), reported the most commonly found barriers to telephone use were; cost, lack of knowledge and an apprehension of features, mobility (not being able to get to the phone) and access.

Cost

For many people with a disability the cost of acquisition and ongoing use of telecommunications is prohibitive. Older adults with health problems reported cost as being one of the major reasons that prevented them from using special features on their phone (Mann, et al., 2005). In Carey et al.'s study (2005) examining use of electronic technologies amongst people with an intellectual disability, expense was listed as a significant barrier by

those who did not use technology. On the other hand, Deaf people¹ (Pilling & Barrett, 2008) found using mainstream technology (e.g., email and text messaging) more appealing to use as there was less stigma and reduced cost than with modifications or special equipment (e.g., TTY).

Role of Communication Partners

Communication partners have been reported as both supporting and hindering access to telecommunications for people with a disability (Greig, et al., 2008). Adults with aphasia often experience a range of sensory, physical and cognitive impairments that negatively affect communication. Greig et al. examined facilitators and barriers to the use of mobile phones in six older adults (40 years and over) with aphasia. Adults, with aphasia, reported speaking with familiar communication partners to be a facilitator, while speaking with an unfamiliar communication partner posed difficulties.

Training

Previous research has also highlighted that training in telecommunication use, or the lack thereof, is a barrier to telecommunication use for adults with aphasia (Greig, et al., 2008) and older adults with health conditions (Mann, et al., 2005). Adults with an intellectual disability also reported the lack of teaching or support as a reason for not using technology (Carey et al., 2005). Families with children and adults who are AAC-users found training in how best to use and programme devices to be limited at times (McNaughton, et al., 2008). It would appear that training plays a significant role not only in the use of telecommunications and AAC equipment.

¹ *People within the Deaf community prefer to use a capital 'D' for 'Deaf' referring to a social movement; seeing deafness as a difference in human experience as opposed to a disability.

Text Messaging

Text messaging provides new opportunities for people with disabilities to access telecommunications for social participation (Pilling & Barrett, 2008; Power & Power, 2004; Power, et al., 2007). Power et al. (2007) surveyed 172 Deaf people about their use of text messaging, TTY (telephone typewriter), relay service, fax and computer communication (online chat groups, email, video calls online etc.). In particular the text feature of mobile phones and email were identified as facilitators of social participation. The authors suggested that these were enabling Deaf people to expand their social networks with hearing people in a way in which, prior to the development of this technology, was not possible. Power et al. (2007) also reported 76% of Deaf participants used text messaging and 73% used email to communicate with hearing friends. This would indicate that texting, in particular, facilitates social participation between people with and without disabilities.

Research Priorities in Telecommunication Use by People with a Disability

Research into the use of telecommunications for social participation in typically developing adolescents is well established. Telecommunications have been identified as being vital in adolescent social participation for various reasons; to maintain social networks (Harley, et al., 2007; Wei & Lo, 2006), to enhance adolescents' identity of self, their identity in a group and enable increased independence from family (Carroll, et al., 2002). Adolescents with a disability have the same need for social participation and a feeling of belonging socially to provide a sense of wellbeing (Berntsson, et al., 2007; Wilson, et al., 2006). Yet, they may experience this quite differently from their peers, with contacts that are less frequent and less intimate (Skar, 2003; Stevens, et al., 1996; Svetaz, et al., 2000). Little is known regarding the role of telecommunications in social participation with adolescents with a disability.

Research is needed to identify the factors impacting on telecommunication use for social participation in adolescents with a disability. Social participation plays an important role during adolescence; providing a sense of identity, well-being and reducing feelings of loneliness (Brage, et al., 1993; Gray, 2002; Stokes, 1985). Adolescents with a disability who struggle to access telecommunications, and are unable to use the modes of communication preferred by their peers are effectively in danger of becoming socially isolated and experiencing loneliness and distress. Therefore, as a starting point, one research priority is to document factors which help or hinder adolescents with a disability when accessing telecommunications. One group that experiences difficulties accessing telecommunications is adolescents with CP. For the purposes of this study, adolescents with CP were selected as a target group to document barriers and facilitators to telecommunications use amongst adolescents with a disability.

Cerebral Palsy

Cerebral Palsy (CP) refers to a number of neurological conditions affecting body movement and muscle coordination (Cerebral Palsy Society of New Zealand, 2008; Macnair & Hicks, 2008; National Institute of Neurological disorders and Stroke, 2008). The term 'cerebral' refers to the brain, in this case to the motor initiation and co-ordination areas and 'palsy' refers to muscle weakness and poor control (Cerebral Palsy Society of New Zealand, 2008; Murphy & Such-Neibar, 2003; National Institute of Neurological disorders and Stroke, 2008).

Symptoms of CP can include; lack of muscle coordination (ataxia), tight muscles and excessive reflexes (spasticity), variations in muscle tone (hypertonic or hypotonic) and difficulties with precise movements. Symptoms of CP vary significantly in type and severity between people. These symptoms are related to which parts of the brain have been damaged

before, during or after birth. Three main types of CP have been identified; 1) Spastic CP causing muscles to be stiff and contract (70-80% of cases) 2) Athetoid (dyskinetic) CP, characterized by uncontrolled, slow writhing movements (10-20% of cases), and 3) Ataxic CP, characterized by low muscle tone and poor coordination (5-10% of cases). Furthermore 'mixed' CP occurs in 10% of all cases, whereby several areas of the brain are involved resulting in a combination of symptoms (Bax, Goldstein, Rosenbaum, Leviton, & Paneth, 2005).

Cerebral palsy is primarily a motor disorder, however, it is often accompanied by other difficulties with sensation, cognition, perception, behaviour and/or seizures (Bax, et al., 2005). For example, CP is often accompanied by visual-perceptual impairment and has been shown to be high (40%) among children (4-21 years) with CP (Bax, et al., 2005). Figures for the prevalence of CP vary from 1.0 to 2.5 per 1000 live births (Cerebral Palsy Society of New Zealand, 2008; N. Murphy & Such-Neibar, 2003) depending on data collection methodology. People with CP make up a significant portion of those people with a physical impairment in the world today. In New Zealand prevalence is around 2.0 to 2.5 per 1,000 live births. Around 7,000 people in New Zealand have cerebral palsy, to some degree, with one third of these less than 21 years of age (approximately 2,330) (Cerebral Palsy Society of New Zealand, 2008). Given that adolescents with CP represent a significant group in our communities today, it is important to examine their social participation and the role played by telecommunications more closely.

Adolescents with CP and Social Participation

Social isolation and loneliness are often reported by adolescents and young adults with CP (Krakovsky, et al., 2007). Krakovsky et al. investigated functional and psychosocial changes in children, adolescents and young adults with CP. Medical charts were reviewed and

telephone interviews were conducted with 30 participants between 11-29 years of age. Findings revealed that the majority of participants reported social losses, such as no longer seeing friends or attending social gatherings (since leaving school). The majority also experienced social and emotional difficulties such as anxiety or aggression towards self or others.

Limited social networks were also reported in a study examining family and peer interactions amongst adolescents with CP (Blum, et al., 1991). In a group of 60 adolescents (12-22 years) with CP, the researchers completed psychological measures and in-depth interviews to examine patterns of family and peer relationships. Results indicated that although most participants (83%) viewed friends as very important, out of school contact with friends was limited with only 16% of individuals having contact with best friends in each other's homes. These findings indicate that adolescents with CP experience restrictions in social participation.

King et al. (2000) examined perceptions of success in a group of ten older adolescents (18-20 years) with CP. Participants defined 'success' as being happy in life and identified three key factors; a) being believed in, b) believing in yourself and c) being accepted by others (belonging). Findings indicate that having a sense of belonging by others is considered important to a sense of well-being in adolescents with CP (King, Cathers, Miller Plogar, & Havens, 2000).

Research into how telecommunications might be used to facilitate social participation in adolescents with CP is limited. Yet this group experiences social isolation and restrictions in social participation as with many groups within the disability sector. However, telecommunications has the potential to alleviate isolation through increased participation. This study will examine telecommunication use in adolescents with a disability, specifically

adolescents with CP. A first step towards expanding our understanding of telecommunications use among adolescents with CP is to examine more closely how they access telecommunications. Closer inspection of the possible barriers and facilitators to telecommunication use by adolescents with CP is needed to improve access and to ensure support services are appropriately informed and targeted. The International Classification of Functioning, Disability and Health was chosen (World Health Organisation, 2001) as an appropriate framework in which to consider these barriers and facilitators.

The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) provides a framework with universal terminology to portray disability (World Health Organisation, 2001). It is based on a bio-psychosocial model whereby disability is presented as the dynamic interaction between a person's health condition (e.g., cerebral palsy), and his or her physical, social, and attitudinal environments (Personal and Environmental Factors). This contrasts with the traditional medical model whereby disability is seen as a predominantly physiological condition that requires a cure (Raghavendra, Bornman, Granlund, & Bjorck-Akesson, 2007; World Health Organisation, 2001). The ICF has been accepted in 191 countries (Tate & Perdices, 2008) and a rapidly expanding literature base exists on the application of the ICF in numerous health conditions (T. J. Howe, 2008; Jonsson, Ekholm, & Schult, 2008; O'Halloran, Hickson, & Worrall, 2008; Raghavendra, et al., 2007).

Within the ICF model, personal factors are those intrinsic to an individual that are not part of his or her health condition. These include factors such as gender, age, personality, previous experiences and social background. Personal factors, in the context of telecommunication use by adolescents with disabilities, include a person's motivation to use

telecommunications, their ability to learn, personal interest level and social skills (World Health Organisation, 2001).

Environmental factors, on the other hand, includes all external aspects to a person's world that make up the context of their life and impact on how they are able to function in that world. Environmental factors include all aspects of the physical world (both artificial and natural), other people, attitudes and values of others and society as a whole, social systems, policies, laws and cultural values (World Health Organisation, 2001). In the context of telecommunication use, environmental factors can be defined, for example, as the availability and accessibility of phones/computers, access to training, personal support, services and funding (Raghavendra, et al., 2007). For the purpose of this study, the focus is on examining environmental factors as opposed to personal factors impacting on telecommunication use.

Environmental factors can be further divided into barriers and facilitators. An individual may experience factors that facilitate participation in real life activities by, for example, an older sibling teaching an individual how to send a text message. They may also experience environmental factors that are barriers to participation, for example, not being able to use the small keys on a mobile phone. The ICF provides a framework for considering the dynamic interaction between these factors and a person's specific health condition (World Health Organisation, 2001). More specifically barriers and facilitators to the use of telecommunications by adolescents with cerebral palsy can be considered within this framework.

Rationale and Research Aims

Telecommunication use by typically developing adolescents enhances social participation and thereby increases feelings of self esteem and well-being. Research has further highlighted that adolescents with a disability experience less telecommunication use

and therefore, are at risk of social isolation. However, research examining the barriers and facilitators to telecommunication use, as experienced by people with a disability, is limited. Furthermore little research exists regarding adolescents with CP specifically and their use of telecommunications for social participation.

It is vital that the barriers and facilitators to telecommunication use by adolescents with a disability are examined. This study forms an initial step in providing important information to ensure that appropriate support and resources are made available, facilitating full and equal social participation. The aim of this study is to investigate which environmental factors present as barriers or facilitators to telecommunication use, as perceived by adolescents with cerebral palsy and their communication partners.

METHOD

A qualitative description approach was selected to provide a detailed account of environmental factors impacting on telecommunication use by adolescents with a disability. Sandelowski (2000) presented this method of research as *fundamental* qualitative description, distinct from other kinds of qualitative description such as; grounded theory, phenomenology and ethnography. The aim of qualitative description is to; a) provide a broad summary of events in everyday terms; b) remain close to the data and the face value of words and events and c) avoid abstract conceptualizing of data in terms of a specific philosophical framework (Sandelowski, 2000). By staying close to the data, qualitative description allows the researcher to capture attitudes, opinions and experiences as expressed by the target population (Sullivan-Bolyai, Bova, & Harper, 2005). It is, therefore, amenable to answering questions of relevance to both practitioners and policy makers (McNaughton, et al., 2008; Sandelowski, 2000)

Qualitative description uses data from multiple sources to describe a person's experiences (Sullivan-Bolyai, et al., 2005). This allows for triangulation of the data, which adds strength to study findings (Patton, 2002). Triangulation was conducted in the following study through interviews with the participant with a disability and an interview with a significant communication partner (e.g., caregiver or parent). Observation of adolescents with CP, involved in the use of telecommunications, provided further data for consideration.

Observations of telecommunication use were conducted prior to the interviews. This period of observation assisted the researcher in the formulation of questions and discussion points for the interviews. In addition, it enabled the development of rapport and provided insight into the communication styles of the participants.

For the interviews, a semi-structured format using open-ended questions was adopted (see Appendix G and H). This allowed participants the freedom to pursue issues that they felt were relevant to their telecommunication use. Questions were further supported with pictures (simple line drawings) to illustrate and enhance comprehension of the questions (See Appendix J and K). An example of a question used was, “Describe or draw a picture of some of the things that help you use the phone or internet (show a picture of a bridge) and things that are not helpful (show a picture of blocks)”.

Participants

Inclusion Criteria Adolescents with Cerebral Palsy

For inclusion in the study, adolescents with CP were required to:

- a) be aged between 15-21 years of age
- b) have a diagnosis of CP confirmed by parent/guardian’s report
- c) currently attend a special education facility in Christchurch
- d) have cognitive abilities suitable for participation in an in-depth interview using his or her preferred means of communication
- e) be able to indicate consent
- f) currently be using some mode of telecommunication (e.g. phone, cell phone, relay system, internet etc),
- g) have a significant communication partner willing to participate in an in-depth interview
- h) use New Zealand English to communicate (whether verbally or non-verbally)
- i) have no reported history of a significant hearing impairment.

Adolescents with Cerebral Palsy

Five adolescents with CP (ACP), who met the above criteria, participated in the study. All ACP had experienced the condition since birth. The mean age of the ACP group was 17 years, 9 months (range 15.9 -20.8, SD = 1 year, 11 months) and included two females and three males. All ACP were raised in New Zealand English-speaking households. Three of the ACPs described themselves as New Zealand-European and two as Māori.

At the time of the study, all of the participants were receiving speech and language therapy intervention to varying degrees in their school settings. One participant was receiving additional home-based speech therapy. All participants were attending special educational facilities which were part of a mainstream High School in an urban setting in New Zealand and were participating in mainstream classes to varying degrees. For full biographical details of the ACP see Table 1.

Table 1 Biographical Details of the Five Adolescents with CP (ACP)

Participant	A	B	C	D	E
Age	20.8	16.4	15.9	17.8	18.5
Sex	Female	Male	Male	Male	Female
Ethnicity	Māori	NZ-European	Māori	NZ-European	NZ-European
Diagnosis /mobility*	CP/wheelchair user	CP, Moderate visual Impairment	CP, Moderate-severe visual Impairment, ASD* /wheelchair user	CP/wheelchair user	CP, Severe visual Impairment/wheelchair user
Home situation	Foster home with two parents	Home with two parents	Home with mother	Foster home with two parents	Foster home with two parents
Education	SEF	SEF	SEF	SEF	SEF
Communication	Severe dysarthria. Some sounds and words. Severely reduced intelligibility for unfamiliar listeners**.	Mild dysarthria Verbal and intelligible for both familiar and unfamiliar listener**.	Verbal and intelligible for both familiar and unfamiliar listener**.	Severe dysarthria Some sounds, no words.	Moderately dysarthric speech with moderately reduced intelligibility for the unfamiliar listener**
AAC use	Communication Board, Gesture Speech Generating Device (SGD) –Dynavox Series 4, Direct access with key guard.			Communication Board SGD – Dynavox Series 4. Access –Scanning, eye gaze/pointing with fist	
Telecommunication use: a) at home	Landline (using a headset), mobile phone (text and photos)	Landline (cordless) on speaker phone, mobile phone (text and emergency calls)	Landline (cordless), Email, MSN messenger, mobile phone (text)	Landline (on speakerphone and using SGD), email (and Bebo), mobile phone (text)	Skype on home computer with touch screen
b) school	Email (using SGD and Access IT)	n/a	n/a	Email, mobile	n/a
PPVT Score	Percentile = <0.1 Age equivalent = 5.10-6.06 (6.02)	Percentile = 5 Age equivalent = 9.02-10.03(9.08)	Percentile = 10 Age equivalent = 9.09-11.00(10.05)	Percentile = <0.1*** Age equivalent = 4.05-5.02 (4.10)	Percentile = <0.1**** Age equivalent = <1.09

SEF = Special Educational Facility (Unit) in a mainstream High School, * Impairment as described per parental report and clinical observation **As per clinical observation. ***Difficulties with selection likely to effect results ****Severe visual impairment restricted administration of PPVT-III V, ASD* = Autistic Spectrum Disorder

Inclusion Criteria for Communication Partners

For inclusion in the study, communication partners (PTR) were required to:

- a) Have a communication partner who was an adolescent (15-21 years) with CP.
- b) Regularly (>4 times a week) observe or be involved with the adolescent when using the phone, mobile and or the internet
- c) Use New Zealand English to communicate
- d) Have no reported history of neurological disorder or significant hearing impairment

Communication Partners

Five communication partners (PTRs), who met the above criteria, participated in the study. Two of the communication partners were the birth mothers and three were foster mothers of the ACP. Four PTRs described themselves as New Zealand-European and one as Māori.

Recruitment of Adolescents with Cerebral Palsy

Ethical approval was gained from the University of Canterbury Human Ethics Committee prior to recruitment of participants (See Appendix A). Seven schools in the Christchurch metropolitan area were contacted; two special schools and five mainstream High Schools with Special Educational Facilities (SEF). Two schools declined to participate. Final selection of ACPs was made from two of the remaining five High Schools.

Information Sheets and Consent Forms

All care was taken to ensure ease of access to written information sheets and consent forms (See Appendix B, C, D, E and F), in accordance with guidelines in the literature (Dye,

Hare, & Hendy, 2007; Howe, Worrall, & Hickson, 2008; Owens, 2006; Worrall, et al., 2005). Consultation was sought from people with cerebral palsy (one adolescent with CP, an adult with CP, a parent of an adolescent with CP) in line with the philosophy ‘nothing about us without us’ (Disabled Persons Assembly of New Zealand (DPA), et al., 2007; McNaughton & Bryen, 2007; Ministry of Health, 2001). Consultation was also sought to determine cultural appropriateness (within Māori culture) of research protocols with Kaimahi Whanau (Family workers), in a local branch of a nationally well recognized community organisation, working in the field of disability.

Information sheets and consent forms used ‘easy-to-read’ language. This was measured using the readability statistics in Microsoft Word. Readability statistics provide information on reading ease and grade level of written text (Comerford Freda, 2005). The reading ease level in the pictorial version of the information sheet was rated at 81.2% with a grade level of 3.0. Both these figures indicate that printed information used in this study was highly accessible in terms of readability.

Sampling of the Adolescents with Cerebral Palsy

Maximum variation, a form of purposive sampling, was used to include a variety of ACP who represented varying levels of competency and variety in telecommunications use (Bailey, Parette, Stoner, Angell, & Carroll, 2006; Patton, 2002). Maximum variation sampling provides maximum coverage of diverse characteristics and is particularly useful in qualitative descriptive studies with small samples (Patton, 2002; Sandelowski, 2000). Ten adolescents initially responded to indicate interest in participation. Participants were subsequently selected to represent a range of ages, degrees of disability, telecommunication use, and cultural backgrounds (see Table 1). The selection process involved consultation with parents/carers

and teaching staff, of the ACP, to discuss suitability of individuals for participation. ACPs nominated a communication partner of their choice.

Procedure

This study was conducted using three main tools. Firstly, a standardized test was administered to ACPs to assess comprehension of vocabulary. Secondly, observations were conducted to gather information on how ACPs used telecommunications and to establish rapport with participants. Thirdly, interviews were conducted with ACPs and PTRs to gather further data on barriers and facilitators to telecommunication use. The research procedure consisted of a number of visits to the participants and separate visits to their communication partners. Visits followed this sequence:

Visit 1: Initial visit to meet the participant, explain the project further, gain written consent and administer the Peabody Picture Vocabulary Test-III (PPVT-III) (Dunn & Dunn, 1997).

Visit 2: Conduct observations of the ACP using some form of telecommunications.

Visit 3: Interview the ACP. Note that more than one visit was required for some ACP interviews.

Visit 4: Conduct an interview with the PTR.

Administration of the Peabody Picture Vocabulary Test-III

The PPVT-III (Dunn & Dunn, 1997) was administered to assess the participant's receptive vocabulary skills (see Table 1 for results). For the purpose of this study all participants were administered Form IIIA. The PPVT-III is reported to be a reliable and valid measure, showing a strong relationship with other language measures (Williams & Wang, 1997). The PPVT-III was chosen because it uses pictures and spoken words rather than print,

making it possible to administer with non-verbal participants. It can also be applied to a wide age range (2.5 to 90+ years). The test was presented in a quiet, separate room at school. Two of the five participants were able to follow the assessment without further adaptations. However, adaptations were made for three participants to allow easier access to the test and to suit the communication styles of the participants. This involved making photocopies of all pages (each containing four pictures) onto A4 sized paper and filing these into a clear plastic leaf file. For one participant (ACP-E) with a severe visual impairment it was difficult to assess how clearly she was able to see the pictures and her results must be interpreted with caution. As the participants in this study differ in cultural background to the original American sample, and in particular for those of Māori ethnicity, results are considered a general indication of the participant's ability.

Observations of Adolescents with Cerebral Palsy)

In consultation with participants, parents/carers and teaching staff, times were arranged to conduct observations either at school and/or at home. The decision to observe at home or school was based on which context provided the participant with the greater access to telecommunications. Observations lasted between 20 to 45 minutes with a mean of 28 minutes per observation (SD = 10.44 min).

Interviews with Adolescents with Cerebral Palsy)

Interviews with ACP were primarily conducted in the home setting. Additionally, four ACP completed part of their interview whilst at school (in a quiet room). These ACP were unable to complete their interviews in one sitting at home due to fatigue and time constraints. Time taken for each interview ranged from 49 to 121 minutes with a mean of 79 minutes (STD = 29). A total time of 6 hours 34 minutes was spent interviewing participants. Family

members/guardians or carers were invited to support the participant in accessing the information and being present during interviews/observations of the participant.

All of the home-based interviews were conducted with a primary carer either present or nearby. The primary carers had an in-depth understanding and longstanding experience with the communication styles of the participant and were often vital in relaying information between participant and interviewer in a more accessible format. For example, the carer would reformulate questions asked by the interviewer so that the participant understood more easily.

The principal investigator, whilst interviewing participants, endeavoured to adjust language-use according to the level of comprehension of the participant, as assessed using the PPVT-III. The principal investigator also utilized visual supports to provide participants with various communication options to choose from. For example (see Appendix J and K), an A4 sheet had six symbol pictures with different options of what might constitute a barrier or a facilitator for the person. Pictures used were 'Picture Communication Symbols' from the software programme 'Boardmaker, Speaking Dynamically Pro' (Meyer-Johnson)

Interviews with Communication Partners

Interviews with communication partners (PTRs) were also conducted in their own home, with the exception of one PTR being interviewed in a private room at a Community Centre. Time taken for each interview ranged from 35 to 89 minutes with a mean of 53 minutes (SD = 22). A total time of 4 hours and 24 minutes was spent interviewing communication partners. All of the interviews were completed in one sitting and were conducted without the ACP present.

Digital Recordings of Observation and Interviews

Each observation session and interview was recorded using a digital video recorder because participants used a wide range of communication modes that could not be recorded by audio recordings alone (e.g. sign, gestures, pointing to symbols, and facial expressions). A Panasonic digital video recorder (Model – SDR-H250) was placed on a tripod facing the participant and interviewer. These recordings were then downloaded to a desktop computer for analysis.

Member Checking

Both the ACP and their communication partner were invited to view any of the transcriptions of the observations/interview as well as video recordings. Participants could give feedback on whether the researcher had accurately represented the thoughts/behaviours of the participant and information was adjusted accordingly. Participants were also free to request that specific information or materials be excluded from the study.

Data Analysis: Qualitative Content Analysis

A qualitative content analysis was utilized as outlined by Graneheim and Lundman (2004). This is the analysis method of choice in a qualitative description study (Sandelowski, 2000). Qualitative content analysis summarizes information content from both verbal and visual data, attempting to understand both its manifest and latent meanings. It remains close to the data, in that there is no directive to re-present the data in any forms other than its own. For example, interviews are transcribed and direct quotes from participants are used in the results section to illustrate key findings. A working definition of ‘Environmental Factors’ and subsequent ‘Barriers’ and ‘Facilitators’ was determined (see Appendix I) based on the International Classification of Functioning Disability and Health (ICF) (World Health Organisation, 2001). Inclusion and exclusion criteria were also determined (see Appendix I)

based on; a) the working definition of Environmental Factors b) discussions with fellow researchers and c) multiple readings of the transcripts.

Procedure of Qualitative Content Analysis

Figure 1 contains a visual summary of the qualitative content analysis process followed in this study as adapted from Graneheim & Lundman (2004).

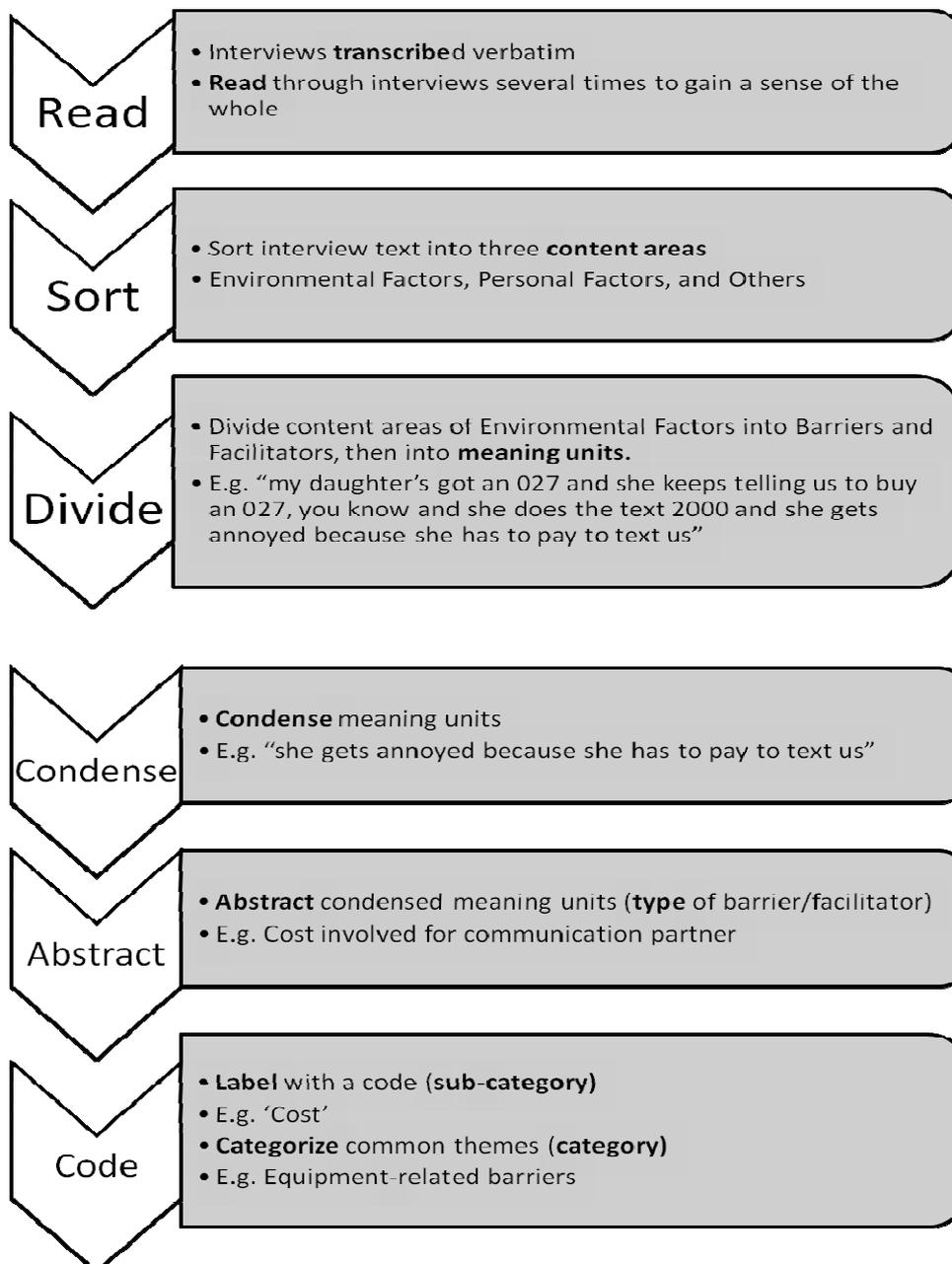


Figure 1 Qualitative Content Analysis Procedures in this Study (adapted from Graneheim and Lundman , 2004)

Repeated readings of interview transcripts were completed to gain a ‘sense of the whole’. Interview text was then sorted into three content areas (Environmental Factors, Personal Factors and Other). All text that did not pertain to barriers or facilitators to telecommunication use was extracted and placed in a separate document. This data contained important information relating to the characteristics of telecommunication use by participants (e.g., frequency of use). However, for the purposes of this particular study, focus was placed upon text relating specifically to barriers and facilitators to telecommunication use.

All text relating to *barriers* and *facilitators* were then extracted into separate text documents. Text was divided into meaning units, that is, sentences or paragraphs that related to each other through their content and context. Meaning units were then condensed; a process whereby the text is shortened but the core is preserved. Condensed meaning units were abstracted and labelled with a code. Codes were compared based on differences and similarities and sorted into categories. A category is a group of content that shares a common theme or topic.

The coding of barriers and facilitators, as well as the grouping of codes into categories, was discussed with other researchers (supervisors and a research assistant). Any differences in judgement regarding barriers, facilitators or categories, between researchers were stated and revised. This was done by reaching a consensus of agreement and in accordance with the predefined inclusion and exclusion criteria (see Appendix I).

Once the coding had been finalised, participants were linked with identified barriers and facilitators. This provided the researcher with an overview of commonalities between participants. For example, whether a barrier was identified by most participants or whether a certain barrier was identified by ACPs and not by PTRs or vice versa.

Rigour

Guideline measures to achieve trustworthiness (credibility, dependability and transferability) in research procedures, as outlined by Graneheim and Lunman (2004), were followed in this study. Credibility of research findings was sought by ensuring that no data was inadvertently included or excluded by adhering to the inclusion and exclusion criteria for barriers and facilitators and by seeking agreement between research assistant, researcher and supervisor. The latter was achieved by coding portions of representative samples (from interviews with both ACPs and PTRs) of transcripts by two other researchers. Discussion between researchers was then undertaken to seek consensus. Credibility was also sought by using maximum variation when selecting participants, to increase the likelihood of answering the research question from different perspectives.

Member checking and triangulation of data were additional procedures undertaken to strengthen the data. Member checking allows participants to confirm whether the researcher has accurately documented their opinions and behaviours. Triangulation occurs when findings from different perspectives confirm similar findings. In this study, findings from interviews, with both ACP and PTR, were compared and further confirmed by the researcher's observations.

Reflexivity

During qualitative research, the researcher is active in data collection and analysis. This calls into question the researcher's qualifications and personal experiences (Patton, 2002). Therefore, it is important to acknowledge and reflect on possible biases. The researcher is a recently qualified speech and language therapist. Prior to training as a Speech-language therapist, she had 13 years of experience in the disability sector with a particular interest and expertise in the area of augmentative and alternative communication (AAC). The

researcher also has a daughter (21 years old) with CP who uses sign, a communication device, and limited verbal abilities to communicate though nonetheless accesses telecommunications on a daily basis. Therefore, the researcher was familiar with many issues that relate to telecommunication use, disability and CP.

The researcher acknowledges that by having a daughter with CP, there is a potential for a certain bias. To minimize this bias, the researcher recorded reflections throughout the process in a journal and discussed these with supervisors. The researcher's daughter did not participate in the study.

RESULTS

Participants identified a total of 66 facilitators and 72 barriers to telecommunication use. These were divided into four categories (people-related, equipment-related, support/training-related and other). Categories were further divided into sub-categories.

Figure 2 provides an overview of the categories and subcategories of environmental factors.

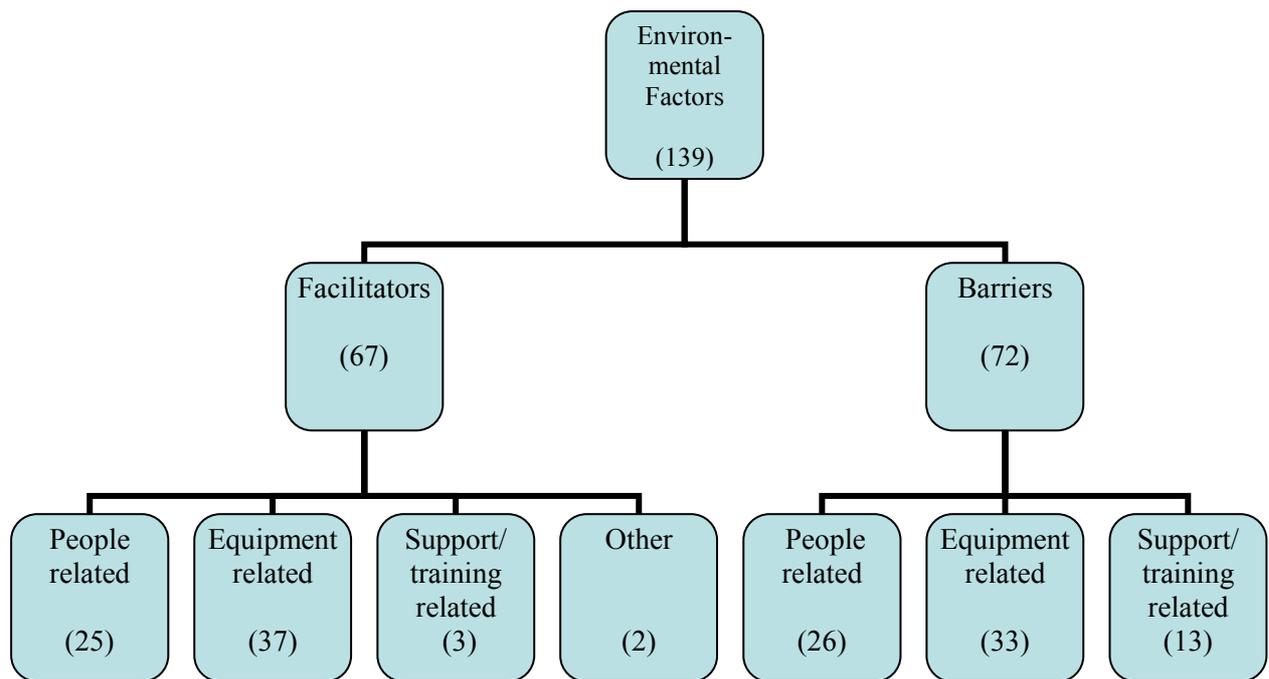


Figure 2 Categories of Environmental Factors: Barriers and Facilitators to Telecommunications use by 5 ACP and PTR
(x) = number of facilitators or barriers identified.

Facilitators to Telecommunication Use

The 67 facilitators for telecommunication use, as identified by ACP and PTR, were divided as follows; 25 were people related, 37 were equipment related, 3 related to training and 2 were ‘other’ facilitators. Figure 3 provides an overview of all the different categories and sub-categories of facilitators, with the number of facilitators listed in brackets.

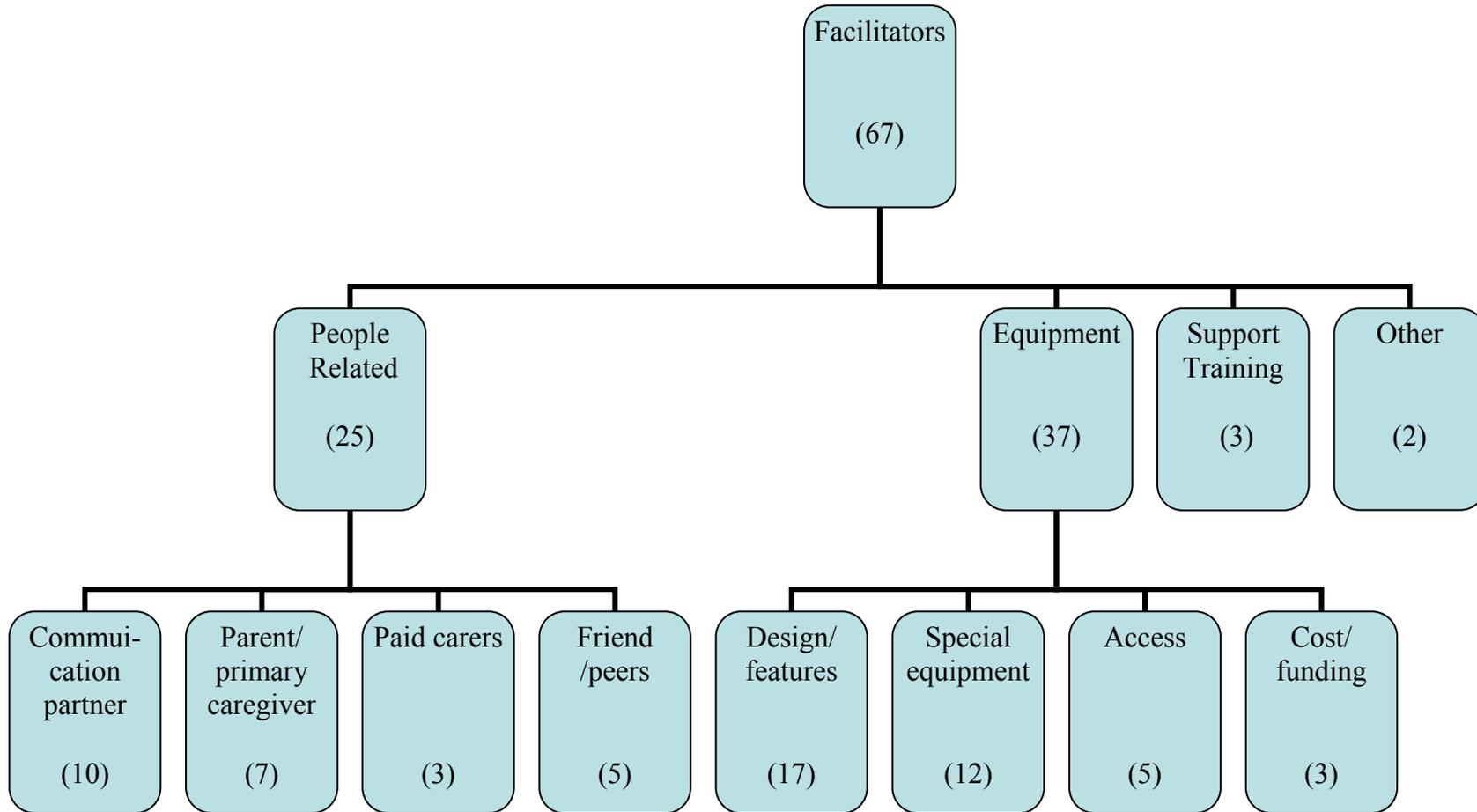


Figure 3 Categories and total number of facilitators to telecommunication use identified by 5 ACP and PTR.
 (x) = number of facilitators identified, grouped under each main and sub-category.

Facilitators: People

People-related facilitators referred to factors involving other people in the ACPs environment who had a positive impact on the ACPs ability to use telecommunications. A large number ($n=25$) of people-related facilitators were identified by ACP and PTR representing 37% of the overall number of facilitators ($n=67$). It was clear that, for many, the social interaction with people via telecommunications was very motivating.

PTR-A: “oh yes it (mobile phone) gives her (ACP-A) pleasure, makes her life more stimulating and...oh she just loves people.”

ACP-C: “I think phone/email/mobile is great..if you get lost, in case you need a friend to talk to. It’s like you are a remote.”

Participants identified 25 people-related facilitators and these fell into four sub-categories; 10 related to communication partners, 7 related to parents/primary carer, 3 related to paid carers and 5 related to friends/peers. A list, with example quotes is given in Appendix L. Table 2 shows all the different people-related facilitators listed under each of the four sub-categories. Key findings for people-related facilitators, according to their sub-categories, are detailed in the following sections.

Table 2 People-related facilitators.

Facilitators identified by 5 ACP and their PTR, listed under each sub-category. (x) = number of facilitators.

Communication Partner (10)	ACP /PTR response	Parent/primary carer (7)	ACP /PTR response	Paid carers (3)	ACP /PTR response	Friends/siblings (5)	ACP /PTR response
Responsiveness	5/1	Facilitates use/training	4/6	Uses telecommunication s in contact with ACP	0/3	Friends giving support	1/1
Timely responses	1/0	Buy/setup equipment	2/5	Specialised skills	0/2	Siblings giving support	0/3
Personal responses	1/0	Specialist skills	2/2	Gives training and support	2/2	Model of fellow AAC-user	0/1
Allowing time to construct message	0/2	High expectations	0/3			Peer language model	0/1
Predictable timing of call	0/1	Parent can access support	0/3			Having non-disabled friends	0/2
Taking time to listen	1/1	Gives literacy support	0/3				
Texting allows Communication Partner to send short/quick message	0/1	Parent willing to learn	0/3				
Texting increases intelligibility	0/1						
Communication Partner able to understand the ACP	1/0						
ACP having lots of contacts	2/2						

Facilitators: Communication Partners

Communication partners were those who were defined as individuals who received phone calls, text messages or emails from an ACP. Although a parent/primary carer can equally be a communication partner, these were recorded in separate categories.

Responsiveness of the communication partner was considered by 6 participants (5 ACP and 1 PTR) as particularly helpful due to increasing enjoyment in telecommunication use by ACPs, and therefore, participation.

ACP-C: “it’s also happy news when I get replies very quickly. I like getting received emails”.

Responsiveness included; receiving emails in return of emails sent, receiving personal and timely responses to text messages and communication partners taking the initiative to phone the ACP to talk and listen. It is, therefore, no surprise that participants further indicated that having lots of people (including communication partners without disabilities) to contact was also important to participants (2 ACP and 2 PTR). For example, in response to a question about describing their ‘dream’ facilitators, one ACP said:

ACP-C: “ah, heaps of friends talking to me...on the internet or usually on MSN or anything like that”

Facilitators: Parents/Primary Carers

Parent-related facilitators represented nearly one-third of all the people-related facilitators (28%). It became apparent when analysing the data that parents/primary carers played a key role in facilitating telecommunication use as well as providing training (4 ACP and 6 PTR). Facilitation ranged from; entering a text, taking a photo, reading out an email for an ACP or setting up the equipment so an ACP could access it themselves. Generally parents also had high expectations of what their young person could achieve (3 PTR).

PTR-A: “cause they’re too tiny to press (referring to the keypads). So I do it for her”

PTR-E: “yeah, because H has lots of original thoughts and ideas... I mean I just know H can be expanded so much.”

Also of note was how parents endeavoured to include ACPs in telecommunication activities of daily life. For example, one family reported the phone being placed on speakerphone during most calls so that the ACP was able to listen in or contribute (via AAC device). Another parent made sure that the ACP had their mobile phone with them when they were going out to ensure they were able to receive messages.

PTR-D: “Cause if I’m ever on the phone I always put it on speaker phone and then ‘D’ has a bit of an earwig in and a comment here and there.”

PTR-A: “she loves having it in her pocket or in her handbag, wherever we’re going, it’s the first thing she says ‘take the phone’ ...just in the hope that somebody’s going to make contact and she’s going to be right there.”

Another facilitator indicated by most participants (2 ACP and 5 PTR) was parental involvement in selecting, purchasing and setting up equipment/phones. Families were actively involved in this process and appeared highly motivated to see that their young people were included in current telecommunication trends to feel ‘normal’ as well as for social and safety purposes;

PTR-A: “because that’s the way the world is going. You just have to keep up with modern trends.”

PTR-B: “well it’s all life skills so I think that’s important...cause that’s a security thing. It’s a link to everybody so I think that’s quite important”

Specialist skills and support of parents were also described as facilitative. Participants (2 ACP and 2 PTR) commented on the particular expertise of parents in programming computers, communication devices or the phone/mobile.

PTR-D: “Look I’ve just changed about ten of his pages (on his communication device) and last night I even changed the swear word page”

Facilitators: Paid Carers

The distinction between ‘paid carers’ and ‘friends’ was at times blurred as participants reported that sometimes ‘carers’ become friends.

PTR-C: “Some of the carers are still ringing to see how we are, or popping round, or he’ll think “can we invite so and so round ... so, yeah...they become your best friend”.

However, when analysing the data it became apparent that although the role of paid carers had some of the characteristics of a friendship, it was a distinct role; one of providing (personal) support in a paid position. Paid carers were also reported to having specialist skills (2 PTR) and providing ACPs with training and support (2 ACP and 2 PTR).

PTR-D: “but his carers have got those skills so that’s good”

Facilitators: Siblings

Families were vital in facilitating the young person to be included in telecommunication use in life. This was confirmed through observations by the researcher. There were three cases in which support was given by a sibling, with two being younger than the ACP. For example, siblings supported the ACP by showing them how to create and send text messages and then practising with them.

PTR-C: “and my daughter’s (ACP’s sister) starting to text him just to make sure that, you know, keep him using it. Texting, yeah so she’s training him as well”

Facilitators: Friends

It was further evident that, for many participants, the personal and social nature of telecommunications was highly motivating. One of the ACPs reported that a friend showing them what to do was helpful and one parent echoed this finding.

PTR-B “N (friend) has set him up a hotmail thing for him”

It was interesting to note that for two of the ACPs, having friendships with typically developing adolescents was helpful for two reasons. Firstly, it gave the ACP friends to use

telecommunications with and secondly, it provided the ACP with an appropriate language model for increasing communication skills generally.

PTR-A: “She likes ..her friends are the able bodied ones. There are some people she’s been in school with, the able bodied, you know the mainstream and we keep in touch with some of them”

PTR-E: “the whole thing about her communication has been around ‘normal’ teenagers and that has increased her vocabulary her understanding, her interest... And lots of different people her own age that haven’t got a disability...and giving different experiences.”

Facilitators: Equipment

Equipment-related facilitators pertained to physical objects or characteristics of those objects which were used to access telecommunications. These included, for example, the design of the key pads on a mobile phone (keys lighting up) or the funding for specialized equipment (a charitable trust supporting the purchase of a touch screen). A total of 37 equipment related facilitators were identified from the data representing 56% of the overall total number of facilitators ($n=66$). These were grouped as follows; 17 related to design/features, 12 related to special equipment, 5 related to access and 3 related to cost. Table 3 provides an overview of equipment-related facilitators. A complete list of reported equipment-related facilitators, with example quotes, is listed in Appendix L

Table 3 Equipment-related facilitators.

Facilitators identified by 5 ACP and their PTR, listed under each sub-category. (x) = number of facilitators.

Design features (17)	ACP /PTR response	Special equipment (12)	ACP /PTR response	Access (5)	ACP /PTR response	Cost (3)	ACP /PTR response
Convenience (mobile)	1/3	Cordless phone	1/1	Access to equipment at home	1/3	Funding given for equipment	0/3
Appearance (mobile)	2/2	Adapted mouse/switches	2/0	Access to equipment at school	2/0	Credit on phone	2/1
Camera facility	1/1	Touch screen	1/1	Com* partner has equipment	1/2	Same network as com. partner	1/1
Font size	3/3	Headset	2/3	Wheelchair access	2/0		
Key pad design		AAC device		Personal ownership	3/1		
– Colour	2/2	– Vocabulary/	2/2				
– (keys/background)		– page setup					
– Button size	3/2	– Key guard	1/0				
– Layout	0/1	– AccessIT	1/0				
– Buttons light up	2/2	– Mounting	2/0				
Ease of use/interface	2/1	Communication board	0/1				
Text facility	2/2	Appropriate wheelchair	0/1				
Screen size and colour	3/3	Use of symbols (PCS**)	0/1				
Speaker phone	3/2	Level of table for wheelchair	2/0				
Phone to suit person	1/0						
Contact list/ phonebook	1/2						
Special features e.g. music	2/2						
Access features	1/1						
Sufficient memory	1/0						

*Com = communication ** PCS = Picture communication symbols (Meyer-Johnson)

Facilitators: Design Features

Design features referred to any aspects relating to how the telecommunications equipment had been planned and constructed. These facilitators ($n=17$) represented 46% of the overall number of equipment related facilitators ($n=37$) and 25% of all facilitators identified ($n=67$). Several design features of telecommunications equipment were considered helpful. These included the use of a big screen and large letter/font size of text on mobile phones (3 ACP and 3 PTR). This was of particular importance to those with visual and/ or physical limitations. Key pad design was also an important facilitator, with many participants (both ACP and PTR) describing factors such as colour, size, layout and buttons ‘lighting up’ as being useful. The texting facility on mobiles was also described as a facilitator (2^{ACP} and 2 PTR) with this form of communication often being preferred above other forms of telecommunication.

PTR-A: “she does love them (phone/mobile/email) all but I guess she does love her mobile (texting) really, the best”

Special features, referred to particular capabilities the telecommunications equipment may possess such as the ability to connect to the internet or create a telephone directory. Those considered important by a number of participants were; having pre-programmed numbers or a contact list (1 ACP and 2 PTR), having a phone (mobile) that looked ‘cool’ (2 ACP and 2 PTR), having access to the internet (from your mobile) and being able to download music or ring tones (1 ACP). Participants and particularly parents (1 ACP and 3 PTRs) were attracted to the versatility/ convenience of mobile phones.

PTR-E: “oh yeah, when we first got this (touch screen) ...the thrill of being able to have all her phone numbers in her phonebook and being able to call someone without me standing there the whole time...her self esteem increases ‘hey look at me what I can do’”

ACP-B: “It (mobile) makes me happy... because of the ring tones.”

PTR-C: “yeah it is, but having the phone there, you know, like I say just text me anytime, but he’s made friends with people around, in the mall, some of the people in the shops?...before I’d panic, I’d be following him around trying to duck behind, people...so yeah the independence that, you know, he said “what if I fall out of my chair?”, “well, somebody can text me and say hey, T has fallen”

Facilitators: Special Equipment

Special equipment, referred to any specialised equipment the ACP required to access telecommunications and facilitators ($n=12$) these represented 32% of the total number of equipment-related facilitators ($n=37$). There was a wide variety of special equipment used in this small group of ACPs; head sets, SGD’s, key guards for on the SGD’s (allowing improved access for pointing) computers/laptops with unique access features, touch screens, specialist software, adapted switches and joysticks, not to mention mounting systems for SGD’s on wheelchairs and the wheelchairs which allowed access to facilities providing telecommunication equipment.

Having a headset was considered a facilitator by five participants (2 ACP and 3 PTR), particularly where physical limitations made it difficult to access standard telecommunications equipment.

ACP-C: “if I had one of those headsets it would be just very easy to use better than the real phone cause the cordless, I always drop them when I’m moving around (in my electric wheelchair)”

Six participants (3 ACP and 2 PTR) also found it helpful to use the speaker phone facility on the phone. One ACP showed a preference for using the speaker phone facility at all times, despite having no reported hearing difficulties or physical difficulties in holding the phone. Another participant (ACP-C) who did find it difficult to hold the phone had an aversion to the speakerphone because he was fearful of different sounds.

For two participants using communication devices, it was found to be helpful to have stored phrases and specific pages set up for using with phone calls or emails. These were personalised to meet the user's needs, either by the speech and language therapist or a parent.

PTR-D: "we always have the phone on speaker phone and he always has this open (referring to 'telephone' page on the DynavoxTM).... this page was made for them (birth parents)"

Parents were often instrumental in developing the vocabulary (words or short phrase) that required programming into the device. They were also able to give physical and verbal prompts to the ACP when navigating their way through pages on the device. One parent described how she had made certain vocabulary (swear words) available but not necessarily on the 'front page' of the device. Availability of vocabulary on communication devices meant that ACP were able to use this vocabulary when using telecommunications.

PTR-D: "I even changed the swear word page so when you open it up it goes whmmmm. and another goes shit"

Facilitators: Access

Access referred to factors that enabled the ACP to physically be able to get to telecommunications equipment. This varied from having broadband and computer access at home, keeping the cordless phone in one's bedroom or having your mobile hung round your neck. Four participants (1 ACP and 3 PTR) considered suitable access to equipment at home helpful and four found it helpful to have suitable access at school (2/2*). Four participants (3/1) indicated that owning your own phone/equipment was helpful.

PTR-C: "yeah, we've got a router, so the one in the lounge stays put, and the laptop can go round the house anywhere and you can use skype on that"

PTR-D: "This is the first year he's had his own phone"

* Number of ACP participants are listed first in brackets followed by a backslash then the number of PTR participants

Observations by the researcher further confirmed that participants having their own, often specialized, equipment was vital in allowing participants to access the phone or computer. For example, one participant required numerous pieces of equipment to be able to write one short email (four lines). These included; a communication device (Dynavox™ - Series 4) plus mounting system for the wheelchair, an adapted mouse (joystick), an 'Access IT' (allows text from a speech generating device (SGD) to be transferred to the computer), electric wheelchair (to access computer suite independently) and suitable computer table (to allow access with wheelchair). Discussions with her speech therapist revealed that equipment had been made possible through various time-consuming funding applications to both government (Ministry of Education, Ministry of Health) and non-government agencies (charitable trusts).

Facilitators: Cost

During interviews, it became apparent that some parents (3) were aware of different funding options which then facilitated the purchase of specialized equipment for telecommunications. Other cost related facilitators reported were having enough credit on the (mobile) phone and using the same network as communication partners in order to save costs.

PTR-C: “yes you can actually get help (to assist with adapting a mobile phone for someone with a visual impairment)” from the foundation for the Blind, yeah but then you can apply for funding”

ACP-C: “M (friend) doesn't. He doesn't have to pay much (keeps talking) M's got 021 (refers to a certain network), my uncle's got 021 and everyone's got 021, apart from my sister”

PTR-C: (laughing) and most of my friends have got 021..so I thought no I'll stick with the same one (refers to plans that offer savings when connecting with others in the same network).

Facilitators: Support/Training

Support or training-related facilitators were all those environmental factors that contributed toward an ACP receiving support or training to be able to access telecommunications. Table 4 gives all of the facilitators identified that related to training/support or were identified as ‘other’. A list of facilitators (support/training or ‘other’), with example quotes, is given in Appendix L.

Table 4 Support/training and ‘other’ related facilitators,
(x) = number of facilitators

Support/training (3)	ACP/PTR response	Other (2)	ACP/PTR response
Access to specialist/technical support (at home or school)	3/4	Having a quiet space	1/0
Access to training at school	1/1	Charity facilitating AAC-user mentor programme	1/0
‘Teacher’ other than parent	0/2		

Three different types of support-related facilitators were identified; access to specialist or technical support (whether at home or at school), access to training at school and having a ‘teacher’ other than a parent. Specialist or technical support was considered by most participants (3/4) as being helpful when accessing telecommunications.

Interviewer; “Anything else that’s helped you?”

ACP-D: (points to communication board) “Speech Therapist”(at school)

ACP-D: (points to communication board) “People who know what to do”

The amount of support received varied per ACP and per school. Type of specialist input also varied from a speech and language therapist or an occupational therapist either at

school or at home, to technical support being given by a family friend. Technical support was also given in the form of programming the computer, the communication device or the phone itself (e.g. pre-programmed numbers).

Specialist programming support was most commonly reported by parents. Parents were also often involved in giving explicit and repetitive teaching, not only in telecommunication use but in social communication skills as these related to using the phone/email.

PTR-E: “and I’d been talking to E (ACP-E) about listening to what people are talking about and then asking questions in things they are interested in...and not always things you’re interested in and I said that’s how you have a conversation.

PTR-E: Oh yeah you have to, the repetition (referring to repetition in teaching). But it pays off in the long run

Two parents highlighted, that although they were involved in providing training and support, there were times when this would be better coming from someone other than themselves.

PTR-B: “It’s better if it comes from somebody else and that person has got better chance of teaching him. If I try and teach him here, it’s like oh mum, yeah yeah I got it Mum”

For four of the ACPs support and training was given by (paid) carers, whether in a structured manner (practising writing emails together) or in a relational manner (by utilizing telecommunications in their way of relating to the ACP:

PTR-D: “with I (Carer) of course he’s always texting him. They go back and forth ..I’m on my way.. whatcha doing?”

Facilitators: ‘Other’

‘Other’ facilitators refer to those facilitators which appeared to stand on their own and did not fit under any of the main categories. Two were identified and were as follows; one participant found it helpful to be in a quiet space when using telecommunications and the

other referred to a mentorship programme. The latter involved one ACP, an AAC- user, who was involved in a mentorship programme organised by a national disability charity. The ACP was partnered with an older AAC-user (who also had CP) as a mentor. Using a landline phone, with their SGDs, and sending text messages played a key role in their friendship.

PTR-D: “How about with P (mentor)... go on, how do you feel when you talk for ages on the phone with P?”

ACP-D: (points on Dynavox™ to) ‘Great’

PTR-D: “yeah...cause P and him got the same language and they understand each other don’t you?”

ACP-D: (smiles)

Barriers to Telecommunication Use as Identified by ACP & PTR

A total of 72 barriers to telecommunication use were identified by ACP and PTR; 26 of these were people related, 33 were equipment related, and 13 related to training. People-related barriers represented 36% of the total number of barriers, equipment 45% and support/training 18%. Figure 4 gives a diagrammatic representation of the three categories of barriers identified, including the 8 subcategories.

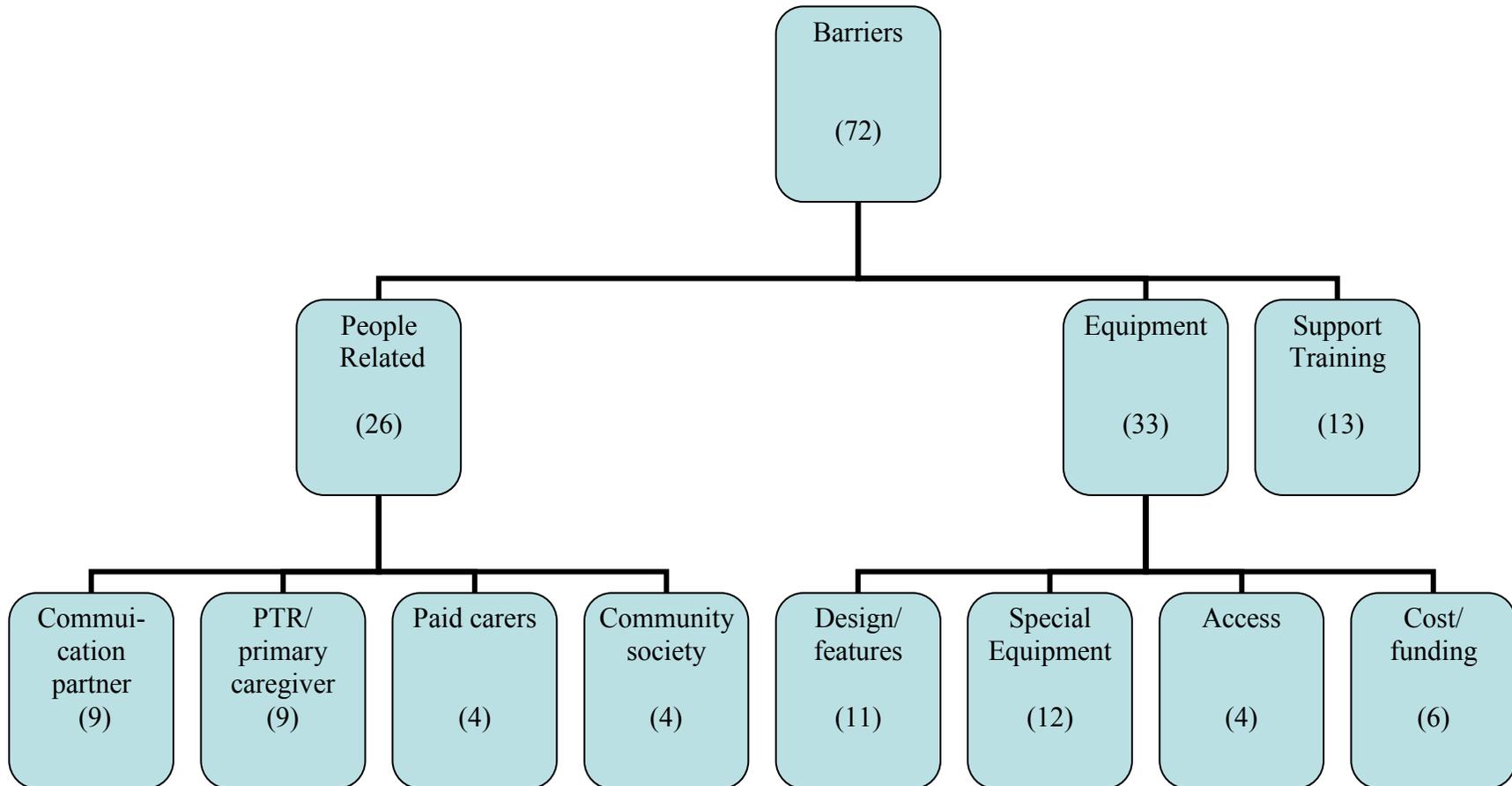


Figure 4 Categories and total number of types of barriers to telecommunication use by five ACP and PTR
(x) = number of barriers, under each main and sub-category, identified.

Barriers: People

People-related barriers were defined as barriers that involved different people in the ACPs life; from direct family to the wider community. Four sub categories were identified with number of facilitators identified as follows; 9 barriers related to communication partners, 9 to parents/primary carers, 4 to paid carers and 4 to community/society. Table 5 contains an overview of all the different people-related barriers under each of the four subcategories. A list of reported people-related barriers, with example quotes, is given in Appendix L. Key findings in people related barriers are outlined in the subsequent sections, according to their sub-categories.

Table 5 People-related barriers: Barriers identified by 5 ACP and their PTR
(x) = number of barriers listed under each sub-categories.

Communication Partner (9)	ACP /PTR response	Parent/primary carer (9)	ACP /PTR response	Paid carers (4)	ACP /PTR response	Community/Society (4)	ACP /PTR response
Limited response	0/1	Parent limits use	3/3	Carer 'taking over' the call	0/1	ACP no longer considered 'cute' by others	0/1
Unexpected responses		Limited time/ patience/ energy to assist	2/3	Different expectations to the ACP	1/1	Neighbours unsure of ACP	0/1
– Bully/swear text	1/0	Limited knowledge	0/4	Not understanding communication/ learning style of ACP	0/2	Lack of disability awareness	0/1
– Sales people	1/0	Limited skills	2/4	Not responding in a timely manner	0/1	Restrictive policies of service provider	0/1
– Answer phone	1/0	Fear of technology/services e.g. Relay	0/2				
– Some contacts cause anxiety	1/0	Not wanting ACP to 'impose' on others	0/1				
Few verbal communication partners	0/1	Limited expectations	0/2				
People talking not listening	1/0	Parent restricting vocabulary selection (device/board)	0/3				
Not understanding speech/communication style	2/0	Interfering when ACP constructing message (on device)	0/1				
Limited contacts	1/3						

Barriers: Communication Partners

Responses from communication partners that were either unwanted or unexpected were identified as a barrier by three ACPS's. For example, one ACP was fearful of 'swearing texts' whilst another was wary of sales people and another of answer phones.

ACP-C: "umm, well I'm alright with answering the phone but I get a bit nervous when a call come up and says "hello we are not home at the moment please leave a message after the beep" and then I just hang up and go nah, it's what I don't like"

Four participants (1/3) sadly noted either a lack of people to contact or a limited social circle. One parent was aware of the lack of responsiveness of communication partners to her daughter's attempts to make contact via the phone.

PTR-A: "it's limited the number of people she speaks to on the phone...it's people like her (birth) mother and our close (foster) family."

ACP-C: "I'm sick of texting my sister...I just want to have friends"

PTR-A: "She doesn't always get a reply (to text message)"

PTR-B: "he would probably not have someone exciting to email."

Barriers: Parents/Primary Carers

Many participants (3/3) noted that although parents were the biggest facilitators of telecommunication use they were, at times, a barrier to its use as well. Restrictions were imposed for a variety of reasons; parent's unwillingness to give others direct access to the ACPs contact details, only allowing access to 'texting' if the ACP had shown the appropriate behaviours required, time and energy limitations on parents' part or not wanting to 'impose' on communication partners.

PTR-A: "the biggest thing is the time it takes and willingness on my part to make it happen for her. I'm happy to do that for her but not like a teenager would on and off the phone all the time for an hour you know. I don't do give her an hour like that."

PTR-A: "the risk is then she'd be bothering people all the time. You know, you do try and limit it sometimes as to how often she sends people a text."

There were also times, reported by participants (2/4) when parents lacked certain skills, knowledge or motivation to assist the ACP in using the phone. It often appeared to be true that the parent was only able to pass on to the ACP as much as they themselves were willing to learn about new technologies.

PTR-A: “but I’m a reluctant starter on the computer and internet...I just want to know the basics that I need, and that’s enough for me”

Parents sometimes limited telecommunication use because of their lack of knowledge about services or technology available. For example, most were not fully aware of services available through the National Relay Service.

PTR-A “I don’t know about that...that scares me. It does sound very involved. I’d rather do it myself”

Another barrier to telecommunication use was parental expectations of ACPs (potential) abilities, noted by two PTRs.

PTR-E: “I think basically H’s learnt as much about Skype as she’s going to learn and that she knows what it’s for and she understands how it’s used. I think that’s as far as it will ever go.”

PTR-A: “really she’ll only ever use the email for social things because of her inability to create new sentences.”

Barriers: Paid Carers

Participants highlighted various barriers that related to paid carers supporting the ACP in using telecommunications; they had different expectations to the ACP, they were not ‘tuned in’ to the ACP, responses were not timely and finally there was a danger that a carer could ‘take over the call’.

PTR-D : “he’s so reliant on others to actually hear it ringing and to answer it and to keep him in the loop, because I find sometimes people start having their little chat and they actually forget that this is D’s phone call and his talk”

Barriers: Community/Society

Three parents highlighted attitudinal barriers that existed in the community relating to a lack of disability awareness generally and specifically regarding the ACP.

PTR-E: “that’s the thing with people with a disability they try to put everyone in the same box no matter what it’s for. It’s really frustrating.”

PTR-B: “but like I say as they get older they lose that cutie cute and it’s a whole different ball game. And it gets harder for them.”

Interviewer: (asking who the ACP uses the phone with) “any sort of neighbours or acquaintances?”

PTR-C: “not yet, they’re still sort of I think, unsure of him”

At other times, barriers existed at the policy level. One parent described a policy of a national service provider of paid carers (a non-government organisation) that restricted the use of telecommunications with carers.

PTR-C: “we just got a new carer from (the NGO) ...he starts tomorrow, so hope, the rules are from there that we are not allowed to trade cell phone numbers...there’s a big clause we have to sign, a thing to say we won’t exchange cell phone numbers, but to me it’s a safety issue if they’re late or we’re not home, you’ve got to use it”

One of the participants, who uses a SGD to communicate, summarised the numerous people-related barriers that are a reality for him as follows. During interviews, the researcher often used communication boards with symbol pictures and simple text to provide communication options (See Appendix J and K). The participant indicated, by pointing at the communication board, the following;

Interviewer: “things on there (referring to communication board) that make it hard to use your cell phone..anything you want to choose?”

ACP-D: “ahmm”

Interviewer: “okay” (places pictures on tray)

ACP-D: Begins to point and looks at interviewer

Interviewer: “The whole page?”(Six options: Problem with people understanding me, problem thinking, people not listening, needing help, takes a long time and someone not having time to help).

ACP-D: (chuckles to confirm)

Interviewer: “the whole page?”

ACP-D – (lots of smiles and vocalisations to confirm interviewer has understood correctly)

Barriers: Equipment

Participants identified a total of 33 equipment related barriers representing 45% of the total number of barriers ($n=72$). These were grouped together as follows; 11 related to design/features, 12 related to special equipment, 4 related to access and 6 related to cost.

Table 6 shows all the equipment-related barriers. A list of reported equipment-related barriers, with example quotes, is also given in Appendix C. Key findings in equipment-related barriers are outlined in the subsequent sections, according to their sub-categories.

Table 6 Equipment-related barriers. Barriers identified by 5 ACP and their PTR
(x) = number of barriers listed under each sub-categories.

Design features (11)	ACP/ PTR response	Special equipment (12)	ACP/ PTR response	Access (4)	ACP/ PTR response	Cost (6)	ACP/ PTR response
Unable to hear ring tone n busy place	0/1	Limited availability	2/3	Limited access to equipment (does not own)	2/2	Special features expensive to use	1/1
Key pad design	3/3	AAC-device	0/1	Unable to access standard equipment	3/5	Running out of credit (mobile)	1/1
– Buttons too small		– Slowness scanning		Not owned phone for long	0/1	Not on same network as com. partner	1/1
– Buttons not segregated enough	1/1	– Vocabulary /page setup restrictive	1/3	Communication partner does not have access to equipment	1/3	Not aware of cost-saving plans	1/2
– Letter size (on keys) too small	3/0	– Accent (USA) effects intelligibility	1/0			Expense of special equipment	0/2
– Buttons do not light up enough	1/1	– Difficult to respond quickly/ flexibly	1/2			Others using up credit	2/0
– Buttons hard to push	0/1	– Computer/phone not converged on device	1/2				
– Layout: wrong colours	0/2	Speaker phone restricts privacy	1/1				
Font (on mobile) too small	2/2	Print too small in the phone book	1/0				
Phone too small	0/1	Time consuming to make message	3/1				
Screen too small (mobile and computer)	3/1	Headset falls off	1/0				
Small memory (on mobile)	1/0	AccessIT failure					
		Equipment failure					

Barriers: Design Features

For most participants (3/3), the biggest barrier in terms of design features were the key pads. Participants highlighted difficulties with buttons that were too small, difficult to push, did not light up or were not well laid out. Font size on mobile phones was often too small. One ACP, with a visual impairment, had enlarged the font while another ACP with a visual impairment, was unaware of this feature on his phone.

PTR-C: “these numbers (letters/digits on keypad) to me look big but he (ACP-TL) couldn’t see them”

ACP-C: “the words are the problem (text size), sometimes, but when they’re up like that (enlarged font) it’s alright to see”

PTR-B: “Well the buttons on the other phone lit up and this one (new one) doesn’t”

PTR-B: “but he just can’t you know and the buttons are really hard to push”

PTR-B: “there’s no segregation in here as to where it all cuts off, it all rolls into one”

PTR-A: “Cause they’re too tiny to press (key pads). So I do it for her “

Barriers: Special Equipment

Many participants (2/3) reported that equipment often let them down; phones broke, batteries went flat, and emails were open to viruses.

PTR-C: “sometimes (he) sort of drops the phone and a scramble round then he runs over it, those sort of, you know, mobility... not often your phone gets squashed by a wheelchair, or usually me standing on it cause he’s dropped it”

The speaker phone enabled hands free access to the phone but equally posed problems with allowing an ACP to have privacy when calling.

PTR-A: “speaker phone’s alright but sometimes I don’t like to eaves drop into M’s conversations though you know, there’s very little privacy”

Barriers: Special equipment for AAC-users

For those two ACP's who used SGD's to communicate, unique equipment-related barriers existed. SGD's allowed the ACP's to have a 'voice' but were very slow at times. This was particularly true for one ACP who accessed his device through scanning.

PTR-D: "original thought, that's all very well, however, you put that into a scanning child and get them to choose every single, your original thought would just take forever"

AAC-users and their parents (1/2), in this study, also expressed their frustration with the limitations imposed by their SGD. Both participants had DynavoxTM -series 4 (Dynavox & Mayer-Johnson, 2006) and therefore did not have computer/internet access nor Bluetooth facilities converged on their devices. This meant that emailing and sending a text message was a time-consuming, laborious and by no means seamless process. This could have been alleviated by participants having access to a newer model.

PTR-A: "Would it (your dream) be if you (ACP-A) could use your Dynavox to make your cell phone work? Would that be helpful?... so you didn't have to fiddle around with the little buttons?"

ACP-A - (nods with emphasis) "yeah"

PTR-D: "and that's why I need to talk to them (therapist support) again about the next Dynavox, because if it's got a computer on it maybe he (ACP-D) can access it easier and it's there when he wants it."

For one of the people using AAC there was the added difficulty of having to use specialized equipment to access the computer through her communication device in order to write an email. The Access-IT piece of equipment, which relays written text from device to computer (via infra-red) failed to transfer each letter. This was particularly frustrating when typing in a password to access the internet.

Vocabulary selection, on devices, or communication boards was at times restricted by parental input. For example, one PTR expressed that she did not want words such as 'bored'

and ‘depressed’ on her daughter’s communication board as she felt there were alternative words that had a more positive connotation that could be used (e.g. instead of bored, the ACP could say ‘I want something else to do’).

PTR-A: “shall we just tell S (interviewer) something that we have on our ‘communication board’... we call it ‘I want to do something else’..because we don’t say ‘bored’ in this house... E we never say ‘bored’ because there’s always something else you can do...it’s like we won’t have ‘I’m depressed’ on her communication board.”

The same PTR was, however, keenly aware of the fine line that existed between allowing a young person to express themselves freely, by giving the necessary vocabulary and restricting vocabulary in order to facilitate perceived positive behaviours. The parent’s description of the ACPs first time at a respite facility was a poignant example of this;

PTR-A: “she wouldn’t be able to send me an email to say ‘Could you come and see me cause feeling homesick’ unless someone put that on as a phrase and it’s not really what you want ... it is hard because the rest of us have the ability to say ‘I don’t like that person looking after me’ or ‘I want to come home’ or ‘I’m not happy here’... Yet you can’t limit her from it ... it’s a fine line isn’t it”.

Difficulties with written text formats (email, text or the ability to write on an SGD) were also noted by participants in this study. Although literacy skills were not measured formally in this study, anecdotal evidence (observations and parent report) indicate that ACPs literacy skills were significantly below the level of their peers. The ability to learn skills such as literacy can be considered a ‘personal factor’ as opposed to an environmental factor. However, how much training is given and the type of literacy programmes used, can be considered an environmental factor. It was beyond the scope of this study to examine this aspect of environmental factors in great depth other than to note the apparent difficulties.

PTR-B: “I would still need to check it (an email/text) and make sure he was putting in the right words here and there um because sometimes he does still come out with it back to front.”

Accessing written text posed particular difficulties for those with limited verbal abilities who were reliant on devices. To access these required either literacy skills or the ability to recognise symbols;

PTR-A: “you know, you’ve got to be able to spell to be able to say something that’s not on the Dynavox (instead of ready-made phrases). And although it’s got predictive text... she would have difficulty reading those and distinguishing which one she wanted so she wouldn’t do it.”

PTR-A “really she’ll only ever use the email for social things because of her inability to create new sentences.”

Barriers: Access

One of the greatest barriers to telecommunication use reported by 3 ACPs and 4 PTRs, was the ACPs inability to access standard or generic equipment due to physical restrictions and design limitations. Access to equipment was further limited due to computers or equipment not being readily available to the participant (5).

PTR-C: “we’ve been trying to find one of those things (gestures to indicate headset) but you’ve got to have the right phone and the attachment and I’m like (shakes her head)... I can’t go to the shop, they haven’t got one or it’s the wrong plug...the plugging system”

PTR-D: “even with the computer I can’t just plug it into the computer and say use it, he still has to have special plugs and everything...and a scanner, that’s why I wanted it (computer converged) on the Dynavox so that sort of stuff is already there”

PTR-D “because if your computer is over there again it’s got to be when it suits everybody else”

Many (4 ACPs) were unable to hold a phone easily or press the keys on a mobile.

PTR-E: “the conversation isn’t as fluent because (when) I’m holding the phone (standard equipment) to H’s ear and she (ACP-E) keeps turning her head all the time she’s not always hearing the conversation at the other end and it gets very stunted. You know it doesn’t flow like it does on the computer (with headset).”

For some ACPs use of telecommunications for social participation proved difficult, at times, due to communication partners of the ACPs needing to have the same equipment as

the ACP (such as VoIP facilities). This was not always the case (1 ACP/ 2 PTR) and therefore limited the ACPs ability to participate.

PTR-E: “yeah..the only way of E (ACP-E) communicating with her (communication partner) is through the telephone (using the skype) so that E is hands free but she (communication partner) doesn’t have the camera.

Barriers: Cost

For some (2 PTR) the cost of special equipment or modifications was prohibitive. The cost of using the special features on mobile phones, such as downloading ring tones or sending photos was restrictive for others (1 ACP and 1 PTR). Two ACPs had difficulties with other people using up their credit.

PTR-C: “I think it’s about \$500 to get (the mobile) adapted (for visually impaired) phone provision”

PTR-A: “we sent a photo to B (friend of ACP-A) once when on holiday. It does cost money so we don’t do it too often.”

ACP-B: “I get very cross when people use up my money”

Barriers: Support/Training

Support/training related barriers referred to factors relating to levels of assistance and training that hindered ACPs from using telecommunications. Thirteen barriers were identified and were grouped under two categories; training related to the ACP and training in the school setting specifically. Table 7 lists all the support/training related barriers identified by five ACPs and their communication partners. This list with example quotes can also be found in the Appendix L.

Table 7 Support/training- related barriers
(x) = number of facilitators

ACP training (6)	ACP/PTR response	Limitations on school support (7)	ACP/PTR response
Needs a 'teacher' other than parents	0/2	Limitations on funding	0/1
ACP lacks knowledge about services e.g. Relay service	1/1	Limited opportunities for use/training	2/2
Takes a long time to get to specialised training facility	0/1	Low expectations	0/1
Cost of getting to specialised training	0/1	Not enough time	1/0
Lack of 1:1 support	2/1	Lack of specialised support	2/2
ACP requires further training	1/1	Lack of privacy/less personal at school	1/1
		Teaching styles vary between home and school	0/1

Barriers pertaining to support/training most frequently referred to by participants were; a) the need for further training for the ACP, b) the time it takes to use telecommunications and therefore the time it takes to support the ACP c) limited access to specialist support at school d) limited training and practice opportunities in schools.

Many participants (2/2) indicated that the lack of training and support at school was a hindrance to learning more about telecommunications. For a number of participants (2/1) there were also times when someone not having enough time to help was a barrier.

PTR-E: "she's not doing email at school as far as I'm aware. It's letter writing, putting the letter in the envelope and taking it down to the post office."

ACP-B: "We don't have email at school"

Interviewer: "Have you (ACP-C with physical and visual impairment) ever had help in terms of using the phone from Speech Therapy, or Occupational Therapy or Physiotherapy?"

ACP-C: "no, no and no"

Interviewer: "how much are they (school) teaching?"

PTR-C: "not much, cause most of this stuff, like I've been teaching".

PTR-A: "she'll always need someone who is able to help her as well."

ACP-D: (points on communication board to identify barriers) "someone not having time to help"

There was need for the ACP to receive further training. For example, one ACP did not know which buttons to press on her mobile while another ACP was unsure of how to use his mobile.

PTR-A: "M doesn't actually know how to use the phone, which buttons to press"

ACP-B: "I'm so confused about the phone all the time."

DISCUSSION

This study investigated environmental factors that influenced telecommunication use as perceived by adolescents with cerebral palsy and their communication partners. Semi-structured in-depth interviews were conducted with five adolescents and their communication partners. Observations of adolescents using telecommunications were also undertaken. Analysis of the data collected revealed a total of 139 environmental factors constituting 67 facilitators and 72 barriers. These factors were grouped into four categories; people-related, equipment related, support/training-related and other.

Five primary findings were identified from analysis of interview transcripts. These findings were; 1) a large and varied number of equipment-related factors reported as both facilitative and obstructive, 2) the significant role of people-related factors and their interrelation to equipment –related factors, 3) the facilitation and obstructions resulting from parental/ caregiver actions or attitudes, 4) literacy support and the selection of vocabulary (e.g., for SGD, communication board or software), 5) the need for further training and/or support. These findings contribute to increasing our understanding of environmental factors impacting on telecommunication use in adolescents with a disability.

Equipment-related Factors

Environmental factors relating to equipment made up half ($n=70$) of the total number ($n=139$) of environmental factors identified in this study. Previous research has also reported a large number of equipment-related factors that impact on telecommunication use by people with a disability. Greig et al. (2008) examined barriers and facilitators to mobile phone use in adults with aphasia and reported that 55% of all environmental factors identified were equipment-related. This indicates that equipment plays a vital role in telecommunication use.

The significant equipment-related factors identified included factors relating to design, specialised equipment and cost and will be discussed in the following three sections.

Design Features

The design of telecommunication devices were of particular significance to many participants in the current study. Participants reported looking for phones that had increased or larger than usual, keypads, screens, and font sizes. They also looked for phones that in themselves were larger. Participants reported the following supporting features of devices; the speakerphone facility, a headset (allowing hands free access) and a preprogrammed contact list. These findings are supported by outcomes from previous studies.

Older adults with chronic health conditions (Mann, et al., 2005), and younger adults with a physical disability (Nguyen, et al., 2007) identified the use of a speaker phone, headset, and larger sized phones, buttons, and screen. People with aphasia found similar features also helpful when using a mobile phone (Greig, et al., 2008). Therefore there is some consistency between the beneficial features reported by older adults with physical impairments and adults with a communication disorder and the participants in the current study. This indicates that accessibility and design issues for telecommunication tools are applicable across the lifespan for people with physical and/ or communication difficulties. However, some design features identified in this study appear to be particularly relevant to adolescents.

Adolescents with CP identified the need for greater access to internet-based telecommunication services via mobile phones. The participants reported a need for wireless internet connections, access to wider social networks through internet chat groups and being able to see people while calling (e.g., video calling or skype™).

ACP-B: “well with an octophone you can go on to the internet, you can go to google and type in u-tube”

This contrasts with older adults with chronic health conditions, such as a sensory (hearing/vision) impairment, physical impairment or learning difficulties, who expressed a need for phone features such as weather alerts, mail services and notifying the user who was at the door (Mann, et al., 2005). Adolescents with CP, on the other hand, expressed a desire for special phone features including the ability to connect to the internet (on their phone) download ring tones, listen to music and have an inbuilt camera.

Furthermore, some of the adolescents in this study found the appearance of the phone (mobile) an important facilitator to their use and to social participation with peers. Phones were perceived as objects to be decorated with one participant covering her keypad with pink glittery stickers. This is consistent with reports from adolescents experiencing typical development who rated the importance of style or fashion as one of the most important factors in initial mobile phone use (Carroll, et al., 2002). Physical appearance becomes a focus and a way of identifying oneself with a group in adolescence (Turkstra, 2000). It is clear from the current study that adolescents with CP do not differ from their peers in this respect.

Many participants reported using the text feature on a mobile phone as the preferred means of using telecommunications. This is consistent with previous findings amongst young people (Carroll, et al., 2002; Harley, et al., 2007; Wei & Lo, 2006). Carroll et al. further reported that texting proved to be a powerful means of establishing and reinforcing individual and group identity. Having a sense of identity and belonging in a group is crucial in this adolescent period (Turkstra, 2000). This could explain why ACPs demonstrated a preference for texting in order to increase social participation and therefore a sense of belonging, particularly with their peers.

Parents of adolescents with CP reported the convenience of mobile phone use as a particularly helpful feature that facilitated greater independence and social freedom. This is

important considering that adolescence is a period in which there is a need to develop skills for independent living and establishment of a personal identity independent of parents (Turkstra, 2000). Adolescents with a disability face considerably more challenges when attempting to increase their skills for daily living as well as their independence from parents (Antle, Mills, Steele, Kalnins, & Rossen, 2008; Taber, Alberto, Seltzer, Hughes, & O'Neill, 2003). Telecommunication use can allow both parents and adolescents the means to facilitate greater independence and manage their own social networks.

Specialised Equipment

The need for specialised equipment was clearly identified by this small group of adolescents with CP. Participants revealed considerable difficulties they experienced in accessing appropriate equipment. A variety of reasons were identified including funding limitations, lack of awareness of available equipment and processes involved in accessing the equipment. Previous studies have highlighted the importance of matching the appropriate telecommunication equipment to the unique needs of an individual with a physical impairment. By completing thorough assessment, training and trialling of equipment, social participation and quality of life can be greatly enhanced (Bryen & Pecunas, 2004; Bryen, Potts, & Carey, 2006; Nguyen, et al., 2007). These findings indicate a need for further investigation and development of the equipment-related assessment procedures for adolescents with CP and their communication partners and for a review of the accessibility of specialist equipment.

Cost

The cost of telecommunication equipment or the use of special features was at times prohibitive to adolescents with CP and their families. Cost, as a barrier to telecommunication use, was previously identified by older adults with health conditions (Mann, et al., 2005) and

adults with an intellectual disability (Bryen, et al., 2007; Carey, et al., 2005). This poses as an extra barrier to adolescents with a disability for two reasons. Firstly, adolescents are not as financially independent as adults (Gray, 2002) and are, therefore, not in a position to purchase telecommunication equipment or services easily. Secondly, due to the nature and level of their impairments, adolescents with a disability are not as likely to gain part-time employment as their peers might (Bryen, et al., 2006), to finance equipment and its ongoing use. The reduced levels of employment among adolescents with CP is also likely to limit their experiences with people outside their immediate family and support network.

People-related Environmental Factors

This study also identified a large number of people-related environmental factors ($n=50$). Interestingly, people-related factors were often strongly interrelated to equipment factors. For example, participants reported that equipment was only useful if there were people who knew how to use it and support its use. Likewise, people were only able to effectively support adolescents with CP in their use of telecommunications if they had the appropriate equipment to do so.

The total of 50 people-related factors identified represented around one third of the total number of environmental factors reported ($n=139$). Interviews revealed that there were often a large number of people involved in an ACP's life (e.g., family members, carers, teacher aides, teachers, therapists, disability support groups). Yet, despite the large number of people involved in an ACP's life, some reported a lack of friends. Previous studies have revealed that adolescents with a disability had friendships that were less intimate or flawed and that they participated in fewer social activities (Skar, 2003; Stevens, et al., 1996). Using telecommunications is one way to develop adolescents' social networks (Brosch, 2008; Carroll, et al., 2002; Wei & Lo, 2006) yet most ACPs in this study found this challenging.

This was due to not only experiencing equipment-related barriers but also experiencing limitations in the most crucial resource of all when using telecommunications, namely people.

People-related barriers ranged from communication partners being few or unresponsive, to a lack of disability awareness in the community. On the other hand participants also reported people related factors that enhanced participation; communication partners allowing adolescents with CP sufficient time to formulate their message and friends and siblings giving practical support. These factors must be further researched and considered in intervention programmes designed to increase the social participation of adolescents with CP.

The Role of Parents

It was overwhelmingly apparent in observations and interviews that parents/primary caregivers were crucial in facilitating telecommunication use for adolescents with CP. They were instrumental in selecting and purchasing equipment as well as organising initial set-up and providing training and practice opportunities. This is vital as parents, of children or young adults who use AAC, reported negative outcomes when they were not involved in the selection of AAC devices for example.

With regards training and programming of equipment, parents in McNaughton et al.'s study (2008) reported they had gained operational competence through training given by a speech therapist, by the manufacturer or by reading the manuals. However, parents found information on how to organise vocabulary and do programming to be limited (McNaughton, et al., 2008). Parents of AAC-users in the current study had varying skills in the programming of the AAC device; one was very skilled and made specific pages for use with telecommunications, while the other left the programming to the speech therapist at school. Both however, expressed their frustration at times at their own limited technological and

linguistic skills regarding programming and use of equipment. They echoed the desires voiced by the other parents for further specialised training related to telecommunication use, not only for themselves but that others would become more involved in the training of their young people.

Conversely, parents and caregivers, in this study, were also reported and observed as creating barriers to telecommunication use. Some parents/ caregivers were limited in their knowledge, skills, time and energy. Parents of children using AAC have previously reported experiencing similar limitations (McNaughton, et al., 2008). There were also parents in this study who restricted the release of contact details of the adolescent. For example, a youth group leader sent text messages via a parent's mobile phone while the ACP had his own phone. Understandably parents are eager to ensure their adolescent is protected from undesirable communication partners. However adolescents, in keeping with their developmental stage, (Turkstra, 2000) need to be allowed the freedom to develop their identity separate from their parents. Telecommunications is one way in which an adolescent with CP is able to develop social networks that extend beyond and separate from the family.

Interestingly, as much as it is praiseworthy that parents played such a facilitative role in the use of telecommunications in the lives of adolescents with CP, it also highlights the dependence of adolescents with CP on their parents. Typically it is in this life stage that adolescents are moving toward a greater independence from parents and seeking to establish an identity separate to parents and family (Turkstra, 2000). The role of peers becomes increasingly important not only in developing a sense of personal and group identity, but in the natural learning that takes place within the context of mutual telecommunication use (Carroll, et al., 2002; Grinter & Eldridge, 2003; Turkstra, 2000). Adolescents in this study did not appear to experience this in the same way as typically developing adolescents, reporting

few social contacts outside of the family and paid carers. There is a need to examine this area more closely in order to increase participation by facilitating natural learning opportunities within the context of mutual telecommunication use with their peers.

The Role of Vocabulary Selection and Literacy Support

The importance of vocabulary use on AAC devices and literacy skills in telecommunications was highlighted by the experiences of study participants. Two adolescents with CP used AAC devices to create and respond to messages on the phone or by email. A third participant used a software programme to assist with letter writing (emails) and relied on pre-stored vocabulary within this programme. Vocabulary selection was at times facilitative, in that participants were able to access appropriate pre-stored phrases for use on the phone relatively easily. Parents in McNaughton et al.'s study (2008) commented on the challenges of selecting appropriate vocabulary for AAC devices and how best to teach the skills needed to create sentences using the vocabulary. Parents in this study also found vocabulary selection challenging and did not always agree with the vocabulary selection in either computer software or device. Furthermore, they struggled to know how best to teach their child how to construct sentences independently as opposed to relying on pre-stored phrases.

The adolescents who used AAC and participated in the study were unable to programme their devices with vocabulary of their choice. This is not uncommon for device users (Lever, 2003). It has implications on the independence of ACP in social participation with adolescents with CP being reliant on others to facilitate the programming of appropriate vocabulary for telecommunication use. In this study, vocabulary selection was at times restricted due to parents limiting the words that were included on the device. For example, swear words or words such as 'bored' or 'depressed'. This potentially limited what

participants were able to express via phone or email. In contrast, a typically developing adolescent is able to choose freely the vocabulary they use, particularly over the phone/email when outside of ‘earshot’ of parents (Carroll, et al., 2002).

Vocabulary selection may have been further restricted by limitations within the device itself. Bryen (2008) examined whether vocabulary required for socially-valued adult roles was available in three widely used symbol sets. Vocabulary lists around adult themes such as college life, sexuality and managing transportation, were generated by adolescents using AAC and other AAC service providers. Discrepancy analysis was then conducted to see whether symbols or symbol combinations existed in the three symbol systems to represent words from the vocabulary lists. On average, only 55% of all the adult-themed vocabulary identified was available in the symbol systems. This suggests that adolescents who rely on symbol support to communicate or construct written messages may be restricted in two ways. Firstly, vocabulary may be restricted by those programming the device, as identified in the current study. Secondly, the symbols required to represent adult-themed vocabulary may not be available. These factors impact on how adolescents with a disability are able to use appropriate vocabulary when using the phone or internet. This is of particular importance in adolescence as the ability to converse with peers around adult-themes is vital in order to develop a sense of individual and group identity (Turkstra, 2000).

Although literacy skills and the provision of literacy training was not formally assessed in this study, anecdotal evidence (observations and parent reports) indicated that composing written text for text messages or emails was challenging for many of the participants. This was particularly true for those two participants who used SGD’s to communicate. Previous research into school aged children with complex communication needs examined the vocabulary of beginning writers (Clendon & Erickson, 2008) and

highlighted the relatively restricted vocabulary of these children. The authors further suggested that one of the primary goals of intervention, with children with complex communication needs, should be to help develop not only face-to-face communication skills but also written communication skills. The inability to communicate effectively in the written form, in the context of this study posed notable difficulties for most participants when accessing telecommunications that require written text (e.g., email and text messaging) and also restricted their ability to do so independently.

The Role of Training and Support in Telecommunication Use

The current study highlighted a lack of technical or specialist support available to adolescents with disability. It appeared that contact with ICT technicians, speech-language therapists and occupational therapists, around telecommunication use, varied from some input within the school or home setting to very little or none at all. Trialing of and training on telecommunications equipment also appeared to be limited. Parents were often unaware of features of equipment that would increase accessibility. For example, one participant with a visual impairment and his parent were unaware of how to change the font size on his mobile phone. This was a feature already installed on the device. Previous studies have highlighted the need for technical support, training and trialling of equipment to facilitate participation in telecommunications by people with a disability (Bryen, et al., 2006; Greig, et al., 2008; Nguyen, et al., 2007). Findings from the current study further support the need to provide training and support for adolescents with disabilities and their communication partners in telecommunication equipment use.

The lack of, or the inadequate nature of, training provided at school was also reported by adolescents and their communication partners in this study. Similar concerns were identified by parents of children and young adults with CP (aged 6-30 years) in relation to

learning about AAC technologies (McNaughton & Bryen, 2007). Parents reported a lack of trained professionals in the school system and that ongoing support for device use was limited. Two of the five participants in this study used AAC technologies when using telecommunication. Limited staff availability, knowledge and skills in the area of AAC and telecommunications technology were identified as barriers by participants in the current study. In addition, the three participants who did not use AAC also reported a lack of training and support available at schools, specifically in the use of telecommunications technology. Some participants reported not having access to email at school and therefore did not receive training in this area. Previous research has documented disparities in access to communication technology between people with and without disabilities (Bryen, et al., 2007; Canadian Council on Social Development, 2002; Kaye, 2000). There is a need for further research into potential disparities in access to telecommunication technologies among students groups in school settings.

Ministry of Education policies promote the incorporation of Information and Communication technology (ICT) in all learning (Ministry of Education, 2003). Electronic-learning (E-learning) can be incorporated into and contribute to each of the five key competencies in the New Zealand curriculum. The e-learning action plan is aimed at all students achieving their potential (Ministry of Education, 2003). The document makes specific mention of supporting Māori and Pasifika students but fails to mention how the specific needs of students with a disability will be met in accessing ICT. Findings from this study suggest that ICT, including telecommunications, are often not easily accessed in the school setting by adolescents with a disability.

Clinical Implications

The findings from this study have a number of implications for professionals working with children and adolescents with disabilities. All participants in the current study reported a variety of barriers to telecommunication use. These comments were made regardless of the severity of communication impairments or levels of comprehension of language. Therefore, clinicians must consider *which* (not if) barriers prevent adolescents or younger children from developing the necessary skills and opportunities to participate in telecommunication use. Once identified, active steps must be taken to overcome these barriers.

One possible step to assist identification of barriers is the development of an audit tool or checklist. This could be developed to assist in the assessment of environmental barriers. Identification of facilitators is also important. There is potential for barriers to be overcome by focusing on and enhancing facilitative factors. For example, a number of participants reported friends and siblings as being supportive in teaching the adolescent how to text. For some participants this was not the case. This could be addressed by facilitating training and mentorship type programmes between adolescents with and without a disability either in the school or in a community setting.

This study identified a wide variety of environmental factors. It is important that clinicians consider the possible influence of a wide range of external factors that can impact on a person's ability to use the phone and internet. This focus on external factors is an extension of traditional therapeutic models of intervention which often focus heavily on internal factors. These external factors reported here relate to equipment, people and training and must be considered and addressed to ensure positive long-term outcomes.

Participants in this study expressed a lack of knowledge about support services available. For example, many of the participants appeared to know very little concerning the

National Relay service (speech-to speech option). Although many communication partners often provided specialist support to adolescents with CP, they also reported limited technical skills (e.g., “I programme the Dynavox™ (SGD). I don’t do computer”). Services for adolescents with CP and their communication partners could be improved by providing further information regarding current services and increasing the amount of specialist support available. Specialist support must include both the adolescent with CP and their communication partners due to the vital support role played by communication partners.

Further clinical implications that can be drawn from this study include; a need to increase training and practice opportunities in educational settings, to facilitate ‘teachers’ other than parents (e.g., utilize siblings or friends), and provide special classes or opportunities to practise telecommunication skills in youth group settings/ community facilities. Finally, as has been highlighted in previous research (Blackstone, Williams, & Joyce, 2002; Smith-Jackson, et al., 2003), manufacturers must further address design issues to increase access to standard telecommunications equipment (Smith-Jackson, et al., 2003) as well as specialised equipment for people using AAC (Blackstone, et al., 2002; Bryen & Pecunas, 2004; Bryen, et al., 2006; McNaughton & Bryen, 2007).

Study Limitations

A number of limitations to the current study must be considered when interpreting findings. Although steps were taken to purposively select participants that represented a wide range of ages, abilities and cultural backgrounds, the small number of participants may not be representative of all adolescents with CP and their communication partners. By adopting a qualitative research design, with observations and in-depth interviews, the comprehensive nature of the data somewhat compensates for the small number of participants.

By narrowing the focus to adolescents with CP, findings may not be applicable to other groups of adolescents with a disability. Cerebral palsy has been defined primarily as a motor disorder, however, it is often accompanied by other disturbances of sensation, cognition, communication, perception, and behaviour (Bax, et al., 2005). It may therefore, be possible to generalise findings from this study to other groups within the disability sector who experience similar impairments. In this study, participants' primary diagnosis was one of CP with certain individuals also experiencing some level of visual impairment, Autism Spectrum Disorder and cognitive difficulties.

A further limitation to the study was that some adolescents with CP had limited expressive communication skills. It was at times difficult to elicit large quantities of information from these participants, particularly those who relied on AAC to communicate. The researcher utilised visual supports to provide participants with various communication options to choose from (see Appendices J and K). It could be argued that the researcher 'fed' the information to participants, thereby manipulating responses. However, all participants showed the ability to clearly indicate their choice as well as indicate when there were no options that represented their point of view on the communication boards. This was confirmed by both clinical observations and parent/ therapist report.

Finally, this study did not include a control group of typically developing adolescents. It is therefore, difficult to identify which environmental factors are common to all adolescents and which are unique to this group of adolescents with CP

Directions for Further Research

This study provides a number of directions for future research. Replication of the study with a larger group of adolescents with CP would further consolidate and expand on findings. Alternatively adolescents with other types of disabilities could be included. Future

research could also consider the inclusion of a control group of typically developing adolescents to examine impairment-specific environmental factors more closely. A wider perspective on the issues involved in telecommunication use by adolescents with a disability could be gained by interviewing a wider range of communication partners (e.g., friends and siblings). Findings from this study could also contribute to the development of an assessment tool or checklist to gather information on environmental factors impacting on telecommunication. This could further support the development of appropriate interventions to increase participation in telecommunication use and thereby social participation.

Conclusions

This study identified many environmental barriers restricting the use of telecommunication use by adolescents with CP. Previous research has focussed primarily on physical barriers experienced by people with a disability when accessing telecommunications use and secondly on the lack of support and training. The findings of the current study confirm previous findings and expand on these by highlighting additional environmental factors unique to this population. These include a wide range of factors related to equipment and people. Parents were identified as playing a vital role in facilitating telecommunication use by adolescents with CP. This can be interpreted as both positive and negative.

A high need for training and support for both adolescents with CP and their communication partners was also identified. Availability and knowledge of appropriate vocabulary and development of literacy and communication skills were also identified as crucial to enhancing the telecommunication use. It was clear that parents and the wider family played a crucial role in facilitating telecommunication use. Therefore, development of training for these groups and adolescents with CP is needed to enhance their social participation through the use of telecommunications.

Some factors that facilitated telecommunication use also presented as a barrier. This highlights the close interrelatedness of environmental factors. For example, there were a larger number of equipment-related facilitators ($n=37$) identified than people-related facilitators ($n=25$), possibly suggesting that equipment is more likely to increase participation than people. However, it is only with the support of key people in an adolescent's life that equipment can be fully utilised.

It was evident in the interviews, and further confirmed by observations, that there were often a large number of people in an adolescent's life facilitating telecommunication use and thereby potentially increasing social participation. These people included first and foremost the immediate family (either foster or birth families), but also relatives, friends, paid carers, speech therapists, occupational therapists, technicians and school staff . However, social contacts with friends/peers appeared to be limited at times. In the light of these findings, it is suggested that clinicians include the wider support network during the assessment and intervention process, in order to extend and strengthen social networks particularly with peers.

This study has also highlighted that although adolescents with CP were supported by schools for their general academic and communication needs, parents and families were primarily responsible for developing skills and opportunities for general telecommunication use. Parents often expressed their limitations; "I don't know a thing about hotmail" yet equally expressed a desire to see their young person develop telecommunication skills in order to participate more socially;

PTR-B: "well it's all life skills so I think that's important (referring to the telephone).

Mobile... well that's important cause that's a security thing. It's a link to everybody so I think that's quite important. Email...I probably wouldn't think as important. Except that it's nice... it's nice that he has that link but it's not a security thing it's a social thing"

The role of telecommunication use in social participation for adolescents with a disability cannot be underestimated. Decreasing barriers and enhancing facilitators to their use makes it possible to enhance social participation and thereby quality of life. This is of particular importance during adolescence which involves transition from school to the wider world. Adolescents with a disability experience many of the challenges and disappointments that their peers without a disability experience during this phase of life. Telecommunications can provide a vital link in maintaining social networks and increasing independence, thereby increasing a sense of well being and inclusion in their respective communities. These are things which adolescents with a disability and their families aspire to and it is fitting to conclude with a glimpse of their 'hopes and dreams'.

Interviewer: "if you were allowed to dream and wave a magic wand, and we're just pretending, what would you have?"

ACP-B: "I'd like to see through the magic of the phone to see people, and do you know how there's a little screen to see people."

ACP-C: "ah, heaps of friends talking to me ... on the internet or usually on MSN or anything like that."

PTR-D: "I just think if S could get a wee bit of a love for the computer and how to work these things it would open up a new world to him in his time...for other people they might be able to do it in half an hour, whereas he might need two hours, but the information stuff will still be there, you know... and he can access it as he, and when he likes... and he's not rushed to do it, he doesn't have to perform, he can have time to think about it and then access it and process it..."

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APPENDICES

Appendix A- Human Ethics Committee approval

Ref: HEC 2008/75

9 July 2008

Ms Sonja Carpenter
Department of Communication Disorders
UNIVERSITY OF CANTERBURY

Dear Sonja

The Human Ethics Committee advises that your research proposal “Using telecommunications for social participation: Facilitators and barriers for adolescents with disabilities.” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 8 July 2008.

Best wishes for your project.

Yours sincerely

Dr Michael Grimshaw
Chair, Human Ethics Committee

Appendix B – Information Sheet

 <h1>Project – TelDisView</h1>	
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Information Sheet for Participants with a Disability (Pictorial version 2.0 13/08/08)

Project Name: Using Telecommunications for Social Participation: Facilitators and barriers for Adolescents with Disabilities.



(The experiences of young people (15 -21 years old), with a physical and/or intellectual disability, who use the telephone/internet for social purposes).

You are invited to take part..... **...in a research project**



Look at this sheet **carefully** or ask someone to explain it to you, to see if you would like to take part.



The project is being run by **Sonja** Carpenter, Dr. **Dean** Sutherland and Dr. **Megan** McAuliffe.



This project will look at how young people with disabilities use:

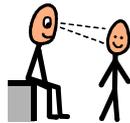


a phone



the internet

Sonja would like to come and **watch** you how you use the phone and internet, for 1-2 hours...



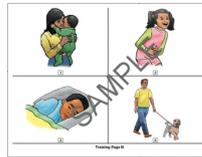
...at **school**



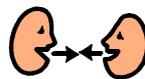
...and at **home**



Sonja will also ask you to look at some pictures to help us understand which words you find easy to understand.



Sonja will **talk** to you about what you find **helpful** and **not helpful** when you use a phone/the internet...



for 1-1 ½ hours.



We can talk by ourselves,



or you can ask someone from your family, a **carer**, or a **friend** to be there with you.

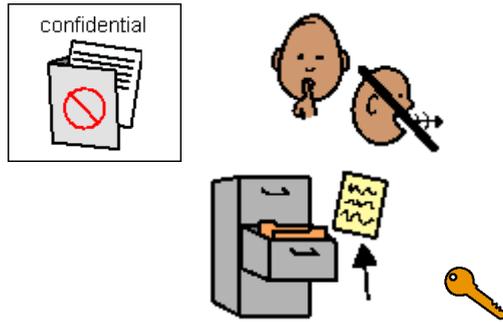
We would also like to talk to someone who you talk with a lot. We will ask them about what they think of how you use the phone/internet.



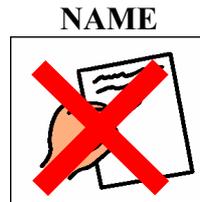
Anything we learn about you will be kept **confidential** (private)

This could be family.. a carer... or a friend

All the information will be kept in a safe, **locked** place.



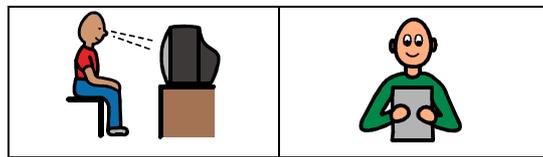
The information (other than the consent form) **will not have your name on it**. It will be confidential.



When we **talk** to you and **watch** you, we will use a video camera to record it. We will also take **photos**. The photos will be used as picture reminders of how you use the phone, for when we talk with you or your communication partner.



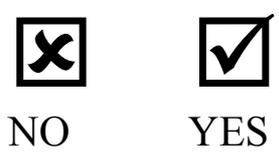
You may look at the video/photos or read any notes taken.



You can decide whether there are parts you do not want used.



Taking part in this study is your choice.



It is **okay** to say ‘**no**’. People at the University of Canterbury, or other places that you get help from, will not be cross with you if you say ‘no’.



If you say ‘yes’ you can still say ‘no’ later on in the study if you want to.

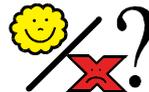


No- later

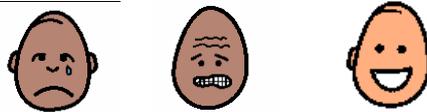
If you say ‘yes’ we will also talk to your parents/carers and your school.



You don’t have to answer any questions you don’t want to.



There may be things that we talk about that make you feel sad, worried or happy.



If you would like to talk more about these things....



...we can help you find a counsellor.

When we are talking with you, you can say ‘stop’ at any time,



to have a **break**,



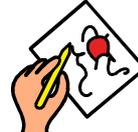
to keep going **another time**,



Or to **stop all together**. That’s ok.



Sonja will show you what she has written, drawn or videoed to **check with you** that she has understood what you said correctly.



When Sonja is finished writing the **report**, she can send a summary (a short version) or come and explain it to you. All the information you give **may help** other young people with disabilities to use the phone more easily.



If you want to take part you will be asked to **sign a consent form**.



Your **parents/carers** will also be asked to **sign a consent form**.



Sonja can **explain** more about the study, answer any **questions** you may have and arrange a time to **come and see you**.



If you would like to take part you can phone Sonja Carpenter
(03) 364 2987 (Extension 4287)
Email Sonja Carpenter
smc183@student.canterbury.ac.nz



Or you can contact:



Dr. **Dean** Sutherland

Room: Office 202 (Unit 11)
Phone ☎: 64 (03) 364-2987
Ext: 7176
dean.sutherland@canterbury.ac.nz



Dr. **Megan** McAuliffe

Room: Office 104 (Unit 1)
Phone ☎: 64 (03) 364-2987
Ext: 7075 (Office) or 7205 (Lab)
megan.mcauliffe@canterbury.ac.nz

Anyone with concerns or complaints about the conduct of a research study can contact: Human Ethics Committee at the University of Canterbury. Email human-ethics@canterbury.ac.nz

Please fill in the slip ✂----- on the next page and return to your school or to Sonja Carpenter. Thank you.



			
Return slip to	school	by(insert date)	Thank you
Draw a circles round the ones you want.			
	 I use the phone/internet sometimes	 I use the phone/internet regularly	 I use the phone/internet often
1. Yes I would like to take part			
2. I am able to use the phone/internet	✓ Okay	✓ ✓ Pretty good	✓ ✓ ✓ Very well
	 Please phone me	 Please email me	 Arrange to visit me to explain more
3. I want more information			
4. No thanks. I do not want to take part			Thank you

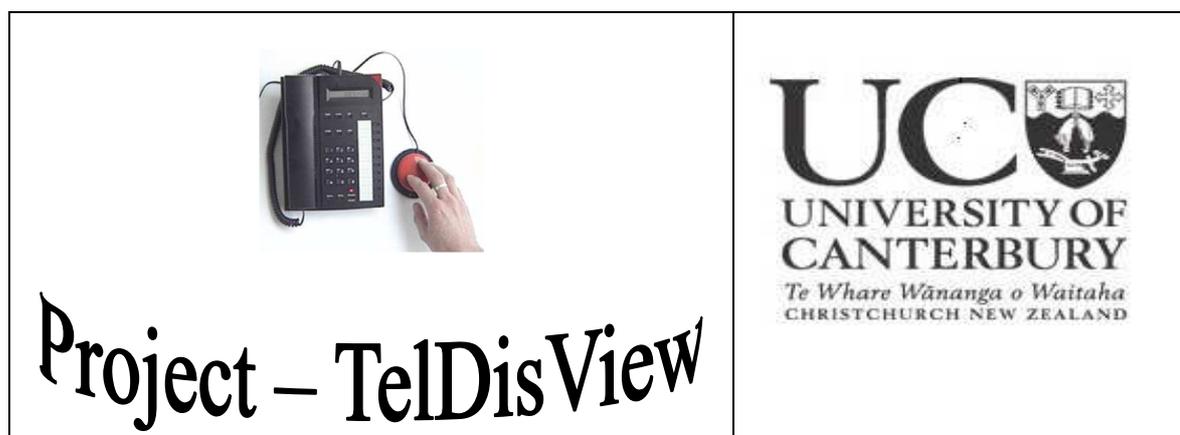
Please write down your contact details



 Name:	 Age	 Home Tel. no.	 Mobile:
 Address	 Email	 School	
Any other questions?		Name of communication partner:	Tel. No.

Flesch reading ease = 81.2, Flesch-Kincaid Grade Level = 3.0

Appendix C – Letter to Parents



13-08-08

Dear Parents/guardians,

We are currently conducting a research project in special educational facilities in Christchurch.

- 1) To describe the characteristics of telecommunication (telephone/internet) use by adolescents (15-21 years old) with a physical and/or intellectual disability for social purposes.
- 2) To describe the facilitators and barriers to telecommunication use for adolescents with disabilities.

The primary researcher is **Sonja Carpenter** (Master's student in Speech and Language Therapy) at the University of Canterbury. She will be supervised by Dr. Dean Sutherland and Dr. Megan McAuliffe. She is a qualified Speech and Language Therapist with many years experience in the disability sector. Sonja has particular skills and experience in augmentative and alternative communication (AAC) as well as being the parent of a 21-year old who uses an AAC device to communicate.

Much has been written about how young people use the phone and internet to maintain contact/friendships with family and friends. However less is known about how young people with a disability use the phone/internet. This information is vital in helping young people with disabilities access the phone/internet in a similar way to their peers and to help cross the disability divide.

To undertake this project we wish to gather information by observing (at school and at home) and interviewing a number of students of varying levels of ability in the use of the phone/internet. We will also interview their communication partners. Please read the enclosed information sheet carefully to read further about the research project.

We would like to ask you for your consent to observe and interview your son/daughter child at school and at home, at a time convenient. You will not be required to be present during observations/interview at school but you are warmly invited to do so if you desire.

Please read the enclosed consent form and return signed (if you are happy to give your consent), either to school or to Sonja Carpenter directly by **(insert date)**. Sonja will then contact you by phone/email/post (whichever you prefer) to arrange a time to visit your child's school and to visit your home.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee.

Please do not hesitate to contact me by phone or email to explain the project further. I would also be happy to visit you, at a location/time convenient to, to explain the project further.

Yours sincerely,

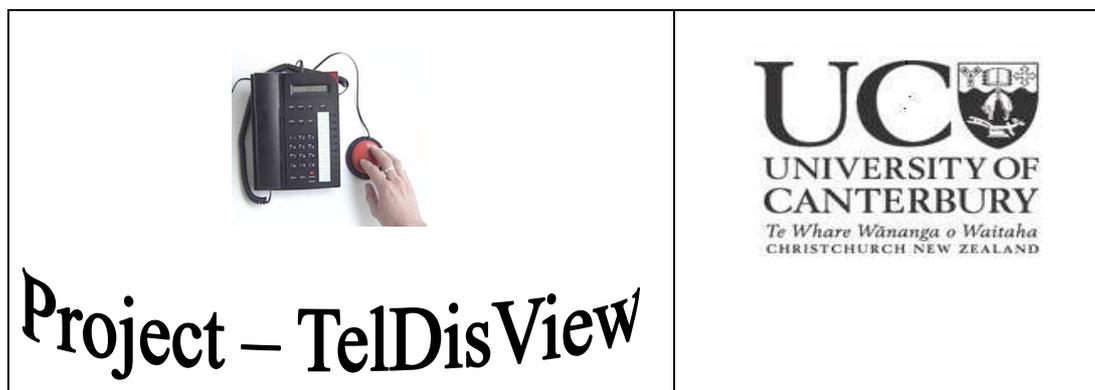
Sonja Carpenter.

Research team

 <p>Mrs Sonja Carpenter Master's student Speech and Language Therapy Department of Communication Disorders, 19 Creyke Road Ilam, Christchurch (03)364 2987 (Ext. 4287) smc183@student.canterbury.ac.nz</p>	 <p>Dr. Dean Sutherland (Supervisor and Lecturer, Department of Communication Disorders, University of Canterbury) Room: Office 202 (Unit 11) Phone: 64 (03) 364-2987 Ext: 7176 dean.sutherland@canterbury.ac.nz</p>	 <p>Dr. Megan McAuliffe (Supervisor and Senior Lecturer, Department of Communication Disorders, University of Canterbury) Room: Office 104 (Unit 1) Phone: 64 (03) 364-2987 Ext: 7075 (Office) or 7205 (Lab) megan.mcauliffe@canterbury.ac.nz</p>
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Anyone with concerns or complaints about the conduct of a research study can contact: the Human Ethics Committee at the University of Canterbury. Email human-ethics@canterbury.ac.nz

Appendix D – Consent Form for Parents



CONSENT FORM for Parents/Guardians (of participants with a disability) Version 2.0 13/06/08

Project Name: Using Telecommunications for Social Participation: Facilitators and barriers for Adolescents with Disabilities.

(The experiences of young people (15 -21 years old), with a physical and/or intellectual disability, who use the telephone/internet for social purposes).

Principal Investigator:

Sonja Carpenter, Master's student, Communication Disorders Department, University of Canterbury.

Associate Investigators:

- Dr. Dean Sutherland, Lecturer, Communication Disorders Department, University of Canterbury.
- Dr. Megan McAuliffe, Senior Lecturer, Communication Disorders Department, University of Canterbury.

Consent

- I have read and I understand the information sheet dated 4th of June, 2008, for participants taking part in the study designed to describe how young people with disabilities use the phone/internet.
- I have had the chance to talk about this study with the researcher/s. I am happy with the answers I have been given.
- I understand that my son or daughter taking part in this study is confidential (private) and that no material which could identify him or her will be used in any reports on this study.
- I have had time to think about whether I would like my son/daughter to take part.
- I understand that taking part in this study is voluntary (my son or daughter's choice) and that he or she may withdraw from the study at any time. This includes withdrawing any information he or she has provided. Taking part in the study or not

taking part will not affect his/her relationship with the University of Canterbury or any other services he/she accesses either now or in the future.

- I agree to digital recordings/photographs being made. These will be to make sure Sonja writes down correctly what she sees and hears. The photos may also be used, as a visual reminder, when Sonja comes to talk to my son/daughter or their communication partner about how he/she uses the phone/internet.
- I agree to photos/digital video recordings being used for clinical training purposes at the University of Canterbury only. **YES / NO**
- I wish to receive a copy of the results **YES / NO**
- I consent to the results of this study being made available for future studies if required. **YES / NO**
- I agree to publication of the results of the project with the understanding that my son's/daughter's identity remains nameless.

I understand that the project has been reviewed *and approved* by the University of Canterbury Human Ethics committee.

**Anyone with concerns or complaints about the conduct of a research study can contact the Human Ethics Committee at the University of Canterbury. Email human-ethics@canterbury.ac.nz*

I hereby consent to my son/daughter (insert name)..... taking part in this study.

Name (Parent/carer): _____

Signature

Address: _____

Telephone number

- Home
- Mobile
- Work

Email

Name of young person: _____ Ethnicity

Age/Date of birth: _____

Type of disability: _____

School: _____

Project explained by: Sonja Carpenter

Project role: Principal investigator

Date: _____

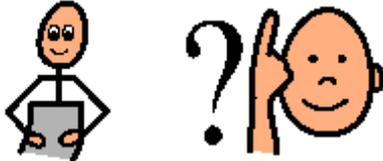
Any other comments:

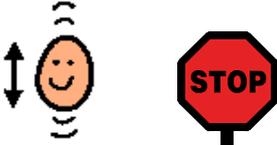
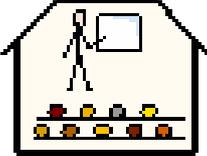
Appendix E – Consent Form for Participants

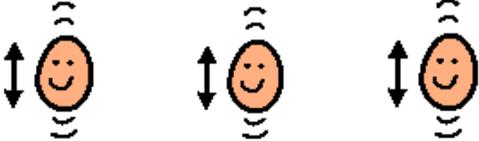
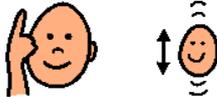
 <p>Project – TelDisView</p>	
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CONSENT FORM for Participants with a Disability (Pictorial version 2.0 13/06/08)

Project Name: Using Telecommunications for Social Participation: Facilitators and barriers for Adolescents with Disabilities. *(The experiences of young people (15 -21 years old), with a physical and/or intellectual disability, who use the telephone/internet for social purposes).*

<p>Principal Researcher: Sonja Carpenter, Master's student, Department of Communication Disorders, University of Canterbury</p>	
<p>Associate Researchers:</p>  <p>Dr. Dean Sutherland, Lecturer. Department of Communication Disorders, University of Canterbury.</p>	 <p>Dr. Megan McAuliffe, Senior Lecturer. Department of Communication Disorders, University of Canterbury.</p>
<p>I have read and I understand the information sheet dated 13th of August, 2008. It talks about people taking part in this study. It aims to describe how young people with disabilities use the phone/internet.</p>	 <p>I read and understood the information sheet</p>
<p>I have had the chance to talk about this study with the researcher/s. I am happy with the answers I have been given</p>	 <p>I asked questions and was happy with the answers</p>

<p>I understand that my taking part in this study is confidential (private). No material which could identify me will be used in any reports on this study.</p>	
<p>I have had time to think about whether to take part.</p>	
<p>I understand that taking part in this study is voluntary (my choice) and that I can stop at any time. This includes taking away any information I have given.</p>	
<p>Taking part in the study or not taking part will not affect my relationship with the University of Canterbury (or any other services I access either now or in the future).</p>	
<p>I agree to digital recordings/photographs being made. These will be to make sure Sonja writes down correctly what she sees and hears.</p> <p>The photos may also be used, as a visual reminder, when Sonja comes to talk to me or my communication partner about how I use the phone/internet.</p>	
<p>I agree to photos and video recordings being used for teaching people at the University of Canterbury only.</p> <p><input type="checkbox"/> NO <input checked="" type="checkbox"/> YES</p>	
<p>I wish to receive a copy of the results</p> <p><input type="checkbox"/> NO <input checked="" type="checkbox"/> YES</p>	
<p>I agree to the results of this study being made available for future studies if required.</p>	

<input checked="" type="checkbox"/> NO <input checked="" type="checkbox"/> YES	
I agree to the results of the project being put into a journal/book with the understanding that I remain nameless.	 Journal
I understand that the project has been reviewed <i>and approved</i> by the University of Canterbury Human Ethics committee.	 Human Ethics Committee
I agree to take part in the study	 me

Name: (please print)



Age:

Date of birth:

Signature: (or thumb print if unable to write)



Ethnicity:

Type of disability:

Date:



Address:

Telephone number:

Mobile number:

Email number:

School:

Project explained by: Sonja Carpenter

Project role: Researcher (Master's student)

Signature:

Date:

Name of communication partner:

Age:

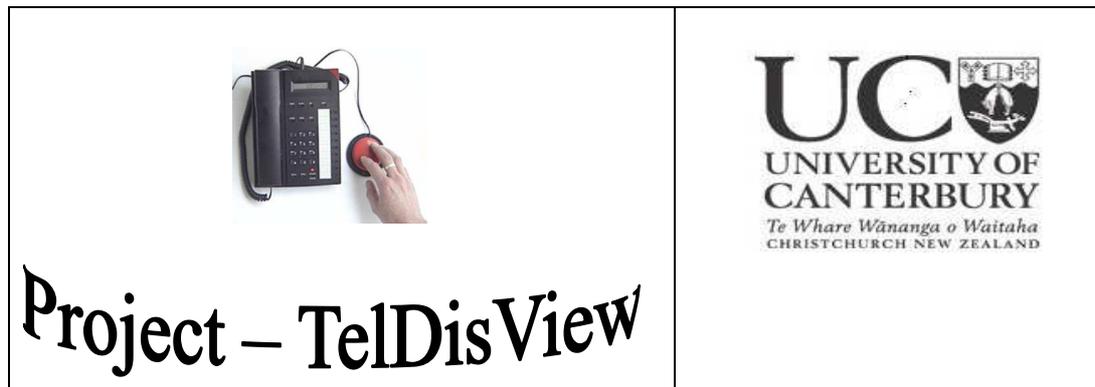
Address:

Tel. No:

Email:

Anyone with concerns or complaints about the conduct of a research study can contact: Human Ethics Committee at the University of Canterbury. Email human-ethics@canterbury.ac.nz

Appendix F – Consent Form for Communication Partners



Consent Form for Communication Partners (Version 2.0 13/06/08)

Project title: *The experiences of young people (15 -21 years old), with a physical and/or intellectual disability, who use the phone/internet for social purposes.*

Principal Researcher:

Sonja Carpenter, Master's student in Speech and Language Therapy, Department of Communication Disorders, University of Canterbury.

Associate Researchers:

- Dr. Dean Sutherland, Lecturer, Communication Disorders Department, University of Canterbury.
- Dr. Megan McAuliffe, Senior Lecturer, Communication Disorders Department, University of Canterbury.

Consent:

- I have read and I understand the information sheet dated 1st of June, 2008, for participants taking part in the study designed to describe how young people with disabilities use the phone/internet.
- I have had the chance to talk about this study with the researcher/s. I am happy with the answers I have been given.
- I understand that my taking part in this study is confidential (private) and that no material which could identify me will be used in any reports on this study.
- I have had time to think about whether I would like to take part.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time. This includes withdrawing any information I have provided. Taking part in the study or not taking part will not affect my relationship with the University of Canterbury or any other services I access either now or in the future.
- I agree to digital recordings/photographs being made. These will be to make sure Sonja writes down correctly what she sees and hears. The photos may also be used, as

Sonja Carpenter Version 2.0 Page 1 13/06/08

a visual reminder, when Sonja comes to talk to me about how the participant uses the phone/internet.

- I agree that the video recordings/photos may be used for clinical training purposes at the University of Canterbury only. **YES / NO**
- I wish to receive a copy of the results **YES / NO**
- I consent to the results of this study being made available for future studies if required. **YES / NO**
- I agree to publication of the results of the project with the understanding that identity remains nameless.

I understand that the project has been reviewed *and approved* by the University of Canterbury Human Ethics committee.

I hereby consent to take part in the study.

NAME: (please print):

ADDRESS:

Tel: Home:

Work:

Mobile:

Signature:

Date:

Communication partner of (Name of young person):

Project explained by:

Project role:

Signature:

Date:

Anyone with concerns or complaints about the conduct of a research study can contact: Human Ethics Committee at the University of Canterbury. Email human-ethics@canterbury.ac.nz

Appendix G - Interview Topics and Questions for Participants with a disability.

Version 2.0 13/06/08

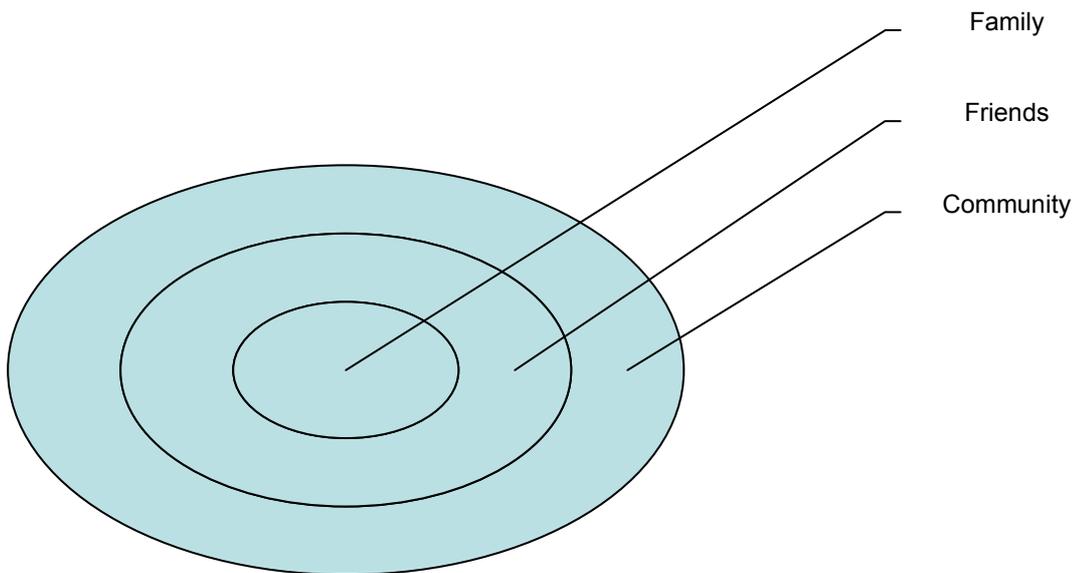


Project – TelDisView

***Topics and questions are subject to change following observations of the participants using the phone/internet.**

1. Who do you use the phone/internet with?

- Draw/create a picture of the different ‘circles’ of people that you communicate with. Write down how often you communicate, using the phone/internet, with all the different people. Divide the circle into segments to represent different ways of using the phone (land line, mobile, email etc.)



2. How do you **feel** about using the phone/internet?

See attached visual prompts with a) pictures representing the different ways we can use the phone/internet and b) pictures of different ‘feelings’.

3. Describe/draw/create a picture of **your ‘dreams’** about how you would like to be able to use the phone/internet in the future.

4. Describe/draw/create a picture of some of the things that help you use the phone/internet (**bridges**) and things that are not helpful (**blocks**). See sketch drawing. [based on Environmental/personal factors from the ICF-WHO (World Health Organisation, 2001)]

5. What is **one thing that would really help you** to improve your use of the phone/internet? (use drawings/point to picture symbols etc.)

6. **How** would you like **to learn** about using the phone/internet? (if no response is forthcoming offer a number of choices e.g. a training course, get someone in my family to teach me, have a 'buddy' who would teach me (peer teaching model), learn on my own with a book or on the computer)

7. **Who** would you like to teach you?

8. **What** would you like to learn about using the phone/internet? (provide visual prompts/choices if the participant has difficulty responding).

9. **Where** would you like to learn? Draw pictures or show photo's of different settings. (home, school, youth group, community group, public library etc.)

10. **Is it important** to you to learn more about using the phone/ internet /mobile? (mark with three different lines for each type of telecommunication on the scale)

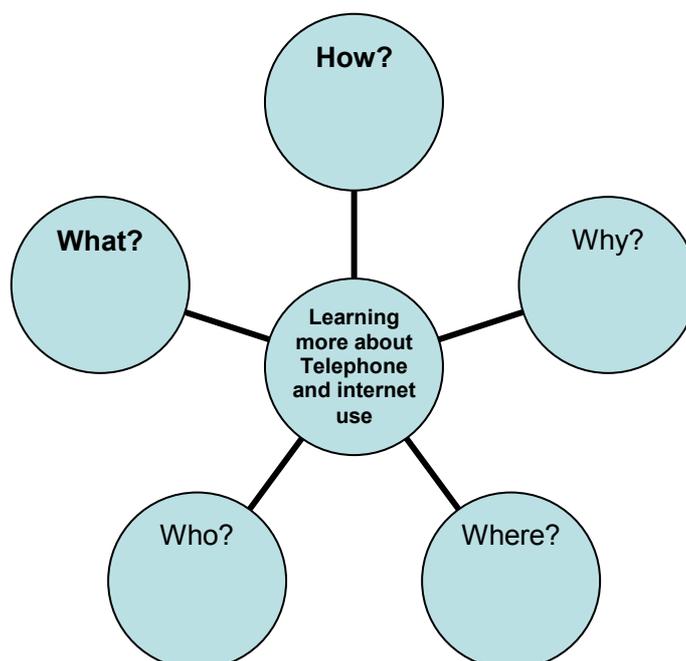
a)

Not really important

Very important

11. **Why** is it important/not important to learn more about using the phone/internet? (what would you then be able to do? What would you use them for?)

(See below for diagram format of questions 6 -11)



Appendix H: Interview Topics and Questions for Communication Partners.

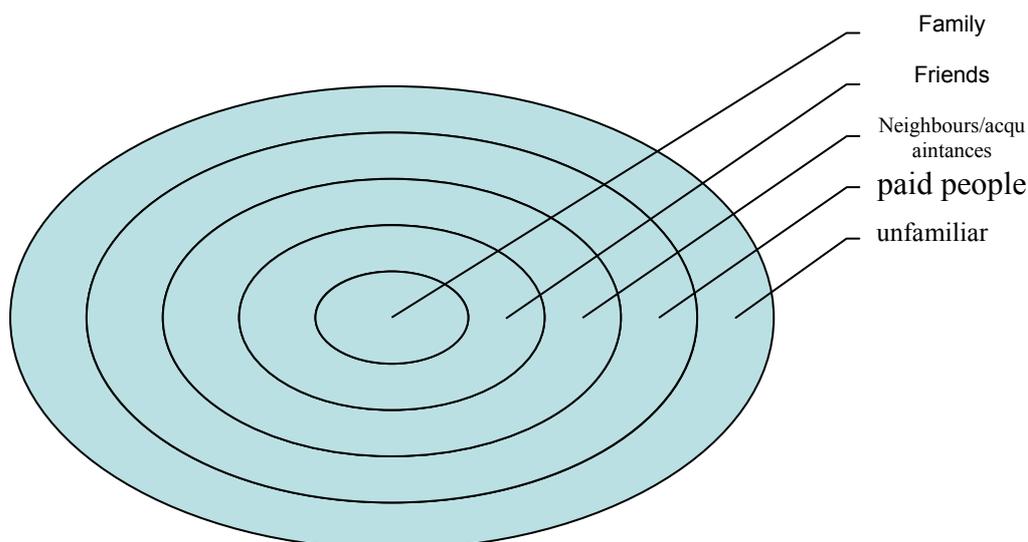
Version 2.0 22/10/08



Project – TelDisView

1. Who does the young person use the phone/internet with? And how often?

- Draw/create a picture of the different ‘circles’ of people that they communicate with. Write down how often they communicate, using the phone/internet, with all the different people. Divide the circle into segments to represent different ways of using the phone (land line, mobile, email etc.)



2. How do you think they **feel** about using the phone/internet?

3. Draw/describe a picture of **your ‘dreams’** for the young person about how they could be using the phone/internet in the future. What do you think their ‘dreams’ are?

4. Draw/describe some of the things that you think the young person finds helpful when using the phone/internet (**bridges**) and things that are not helpful (**blocks**).

[based on Environmental/personal factors from the ICF-WHO (World Health Organisation, 2001)]

5. What is **one thing that you think would really help** the young person to improve their use of the phone/internet? (this could be something you would like to improve on or something you would like to see the young person improve on)

6. **How** would you or the young person like **to learn** more about using the phone/internet?

a) you

b) the young person

7. **Who** would you like to **teach** you/the young person?

a) you

b) the young person

8. **What** would you like **to learn** (or what would you like the young person to learn) about using the phone/internet?

a) you

b) the young person

9. **Where** do you think the young person (or you) would like to learn? (e.g. home, school, youth group, community group, public library etc.)

a) you

b) the young person

10. **Is it important to you** to learn more about using the phone/ internet?
(mark on a scale – place different marks for phone, mobile, internet and relay)

a)

Not really important

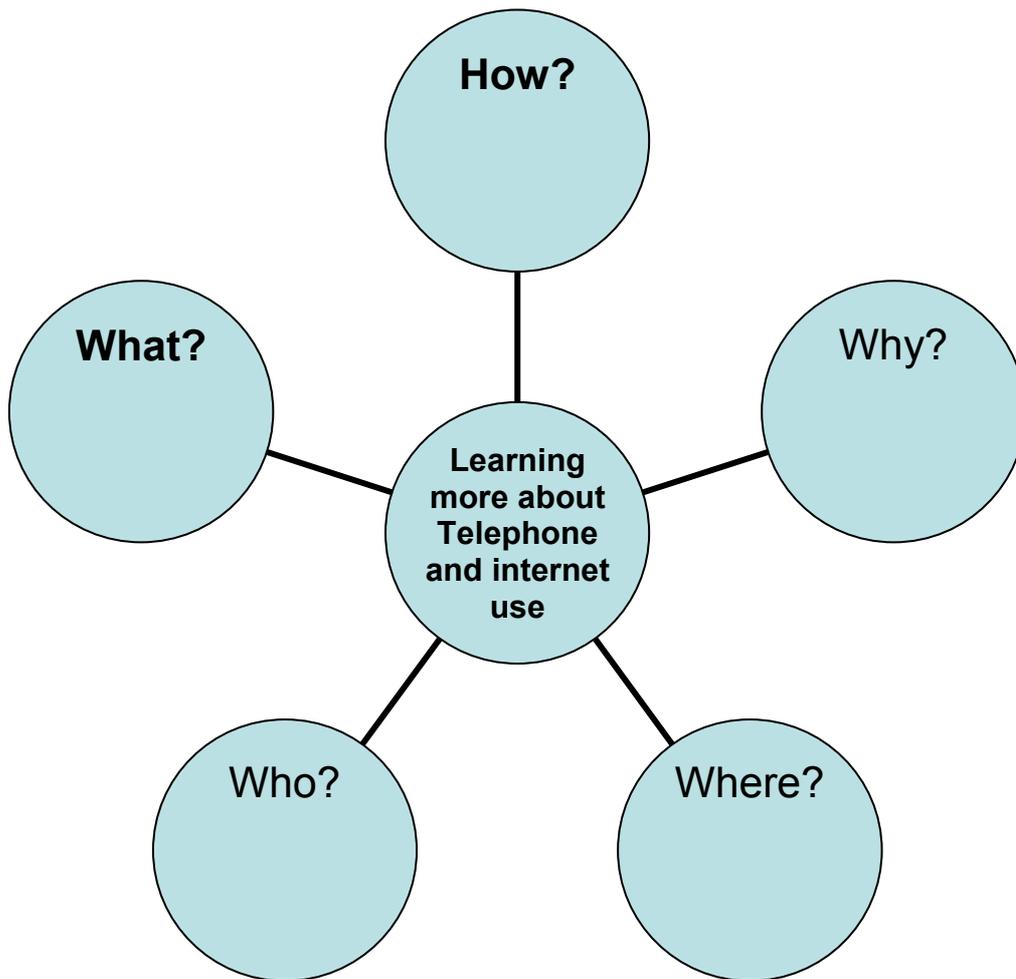
Very important

b) Do you think it is important to **the young person** to learn more about using the phone/internet?

Not really important

Very important

11. **Why** is it important/not important to learn more about using the phone/internet? (what would you/the young person then be able to do? What would you use the new skills for?)
(See below for diagram format of questions 6 -11)



12. Any other comments?

World Health Organisation (2001). *International Classification of Functioning, Disability and Health: Introduction*. Retrieved 15/03/07, from <http://www.who.int/classifications/icf/en/>

Appendix I - Working definition: Barriers and facilitators

Environmental Factors are defined (WHO, 2001, p. 213) as:

“All aspects of the external or extrinsic world that form the context of an individual’s life and, as such, have an impact on that person’s functioning. Environmental factors include: the physical world and its features, the human-made physical world, other people in different relationships and roles, attitudes and values, social systems and (rehabilitation and government agencies) services and policies, rules, and laws.”

Facilitators = environmental factors that support *participation* in telecommunication use

Barriers = environmental factors that hinder *participation* in telecommunication use

Participation = involvement in life situations (restrictions = problems in involvement)

Definition of inclusion/exclusion criteria for coding barriers and facilitators (B/F) from data (interviews)

Inclusion criteria

- Items/issues *specifically spoken* about by either participant or communication partner as something that helps or hinders them in using telecommunications.
- Issues/items *spoken about in very clearly positive or negative terms* relating to telecommunication use, even when not specifically labelled as a help or a hindrance.
- Items/issues that participants/ com partners *speak specifically about that hinder or help communication in general terms but therefore impact, by default* on how participants access telecommunications.

Exclusion criteria

- Things people *think will make it easier/harder to use* telecommunications, but not necessarily experienced themselves (hopes and dreams). B/F are often inferred in these hopes and dreams but not explicitly stated.
- *Not an extrapolated B/F* i.e. things that could be interpreted or inferred from what participant says but are not clearly stated.
- When *stating/describing* what they currently do but not necessarily attach a judgement/value to whether it is helpful or not e.g. what they are good at doing/not good at doing, their personal strengths and weaknesses.
- When *stating describing what the phone is good/not good for* (advantages) e.g. for security purposes and not talking about a B/F as such. Unless they say something like; having/using the text feature means I can leave my son on his own at the mall, to meet others, and know he is safe...therefore the texting/mobile has facilitated greater independence/social opportunities.
- *Items/issues the investigator suggests* which are confirmed with a yes/no by participants but they do not extend on in any detail themselves. *Exception to this may be the AAC users* who have very limited expressive communication skills and rely on the offering of ‘options’ by the investigator to be able to indicate by confirming an ‘option’ what they think/feel.

World Health Organization (2001). International Classification of Functioning, Disability, and Health: ICF.

Geneva: World Health Organization

Appendix J: Summary of Visual Aids used in the Semi Structured Interviews

Question: who do you talk to on phone/mobile/email?

Card 1:

Family: Mother, father, step parent, Carer, foster parent, grandfather, grandmother, brother, sister, Uncle, aunt, cousin, nephew, niece, step brother, step sister, half brother half sister.

Card 2:

Friends: School, youth group, church, street, neighbour, friend.

Community: School, doctor, Church, Hospital, work, sports

Facilitators and Barriers

Facilitators

- A) Symbol pictures of possible facilitators were printed in black and white, using Boardmaker (Meyer Johnson) and glued on to green card (referred to as 'green lights' or 'bridges', 'things that help you').
- B) Six boxes (two rows of three) were printed on an A4 sheet (landscape), each picture was 5.5 cm by 6.5 cm with the text typed below the picture using 'Bold' size 20 font.
- C) Text as follows:

Card 1	Card 2	Card 3	Card 4
someone helping	Encouragement	Technical support	Space
people giving me time	Rewards	Friends showing	Wheelchair
People who know what to do	Special class	me	access
Having a good computer	Teacher	Family helping	Suitable
		me	phonebook
Having the right phone	Relay system	Special switches	Speech Therapy
Having money	Headphones	Special software	Occupational
		Help at school	Therapy
			Physiotherapy

Barriers

Same procedure as above except possible 'barriers' were glued onto red card and referred to as 'red lights', things that get in the way', 'blocks', or things that don't help.

Card 1	Card 2	Card 3	Card 4
Get tired	People not taking time	Problem with my hands	Problem with people understanding me
I find it difficult	Problem with the keys	Problem with my body	Problem thinking
I don't understand how to do it	Problem seeing	Thinking of the letters	People not listening
I feel left out	Problem hearing	Thinking of a sentence	Needing help
I am not sure which one to use	I don't have my own	Problems reading	Takes a long time
I need a new model	Problem with money	Problems writing	Someone not having time to

help

Question; How do you feel about using the:

- A) Mobile
- B) Telephone
- C) Email

Pictures were printed in black and white, 5.5 x 6.5 cm size buttons, text typed above the picture in size 20 font. Positive emotions glued on to green card and negative emotions glued on to red card.

Positive emotions

cool	helpful	nice
content	great	okay
comfortable	great idea	relaxing
excited	happy	relaxed
funny	like	satisfied

Negative emotions

annoying	difficult	mad	uncomfortable
angry	depressed	not helpful	unsure
anxious	embarrassed	nervous	upset
awful	frustrated	not funny	unhappy
	I don't like		
bored	that	not happy	worried
confused	lonely	sad	I don't know

Question; where would you like to learn about using the phone/email?

Symbol pictures of possible places were printed in black and white, using Boardmaker (Meyer Johnson) and glued on to pink card. Six 'buttons' to an A4 sheet, each picture was (size) with the text typed below the picture using 'Bold' size? font. Text as follows:

1. Home
2. School
3. Church
4. Work
5. Youth group
6. Library
7. Elsewhere (asked verbally)

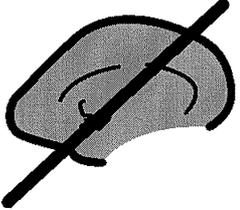
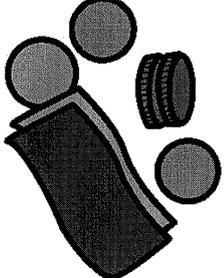
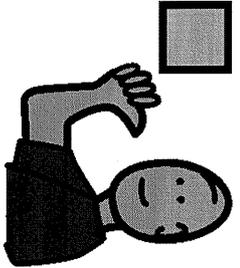
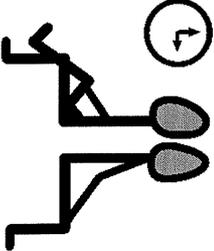
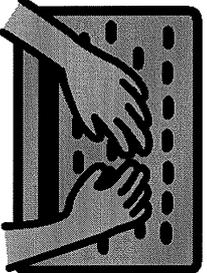
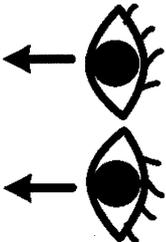
Question; who would you like to teach you about the phone/email?

Card 1. sister, friend, grandparent, teacher aid, youth group leader,

Card 2. Occupational therapist, Physiotherapist, Speech therapist, Teacher, Parents, brother.
 Asked verbally; "Anyone else?"

Appendix K: Examples of visual supports used during interviews with ACP

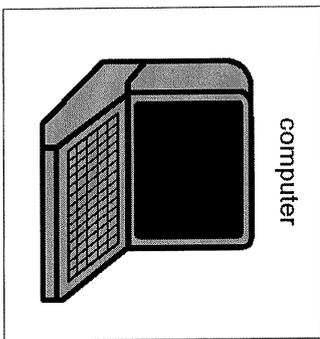
Things that make it difficult for you to use the phone/mobile or email (glued on to red card and described as 'red lights' or 'blocks')

<p>Problem hearing</p>	 <p>hearing impaired</p>
<p>Problem with money</p>	 <p>money</p>
<p>I don't have my own</p>	 <p>mine</p>
<p>People not taking time</p>	 <p>impatient</p>
<p>Problem with the keys</p>	 <p>keyboarding</p>
<p>Problem seeing</p>	 <p>look</p>

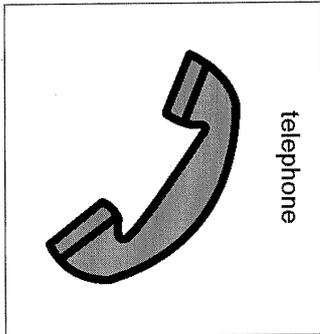
Appendix K (cont.) Examples of visual supports

Things that made it easier for you to use the phone/mobile or email? (glued on to green card and described as 'green lights' or 'bridges'.

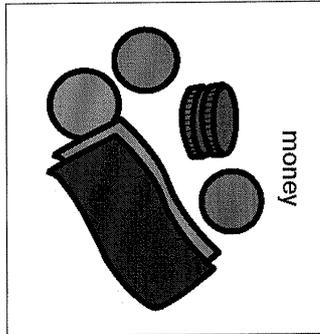
**Having a good
computer**



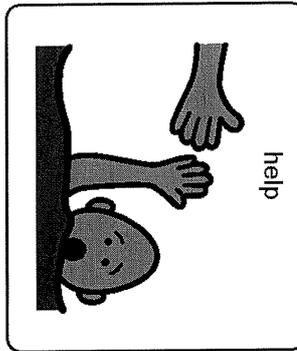
**Having the
right phone**



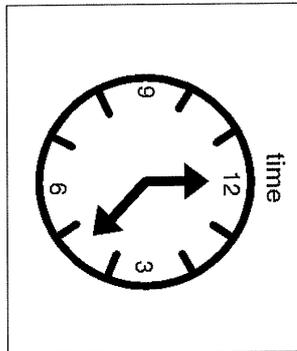
Having money



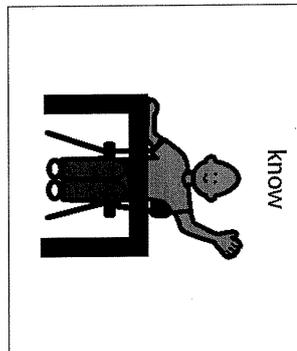
Someone helping



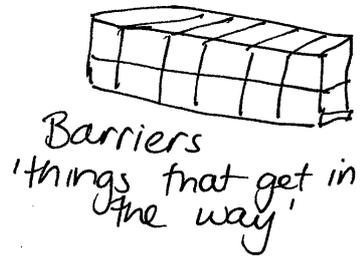
People giving me time



**People who
know what to do**

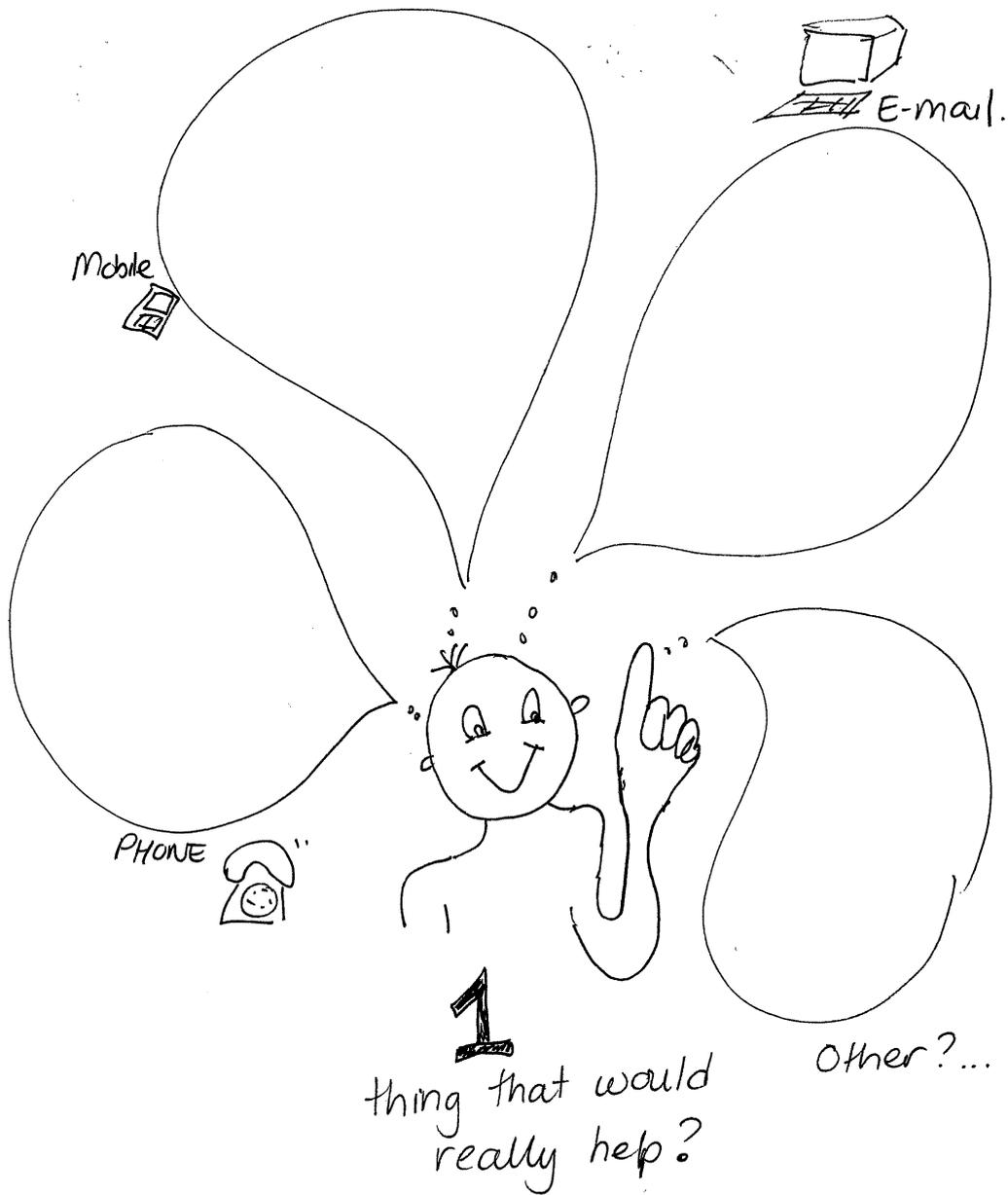


Appendix K (cont.) Examples of visual supports



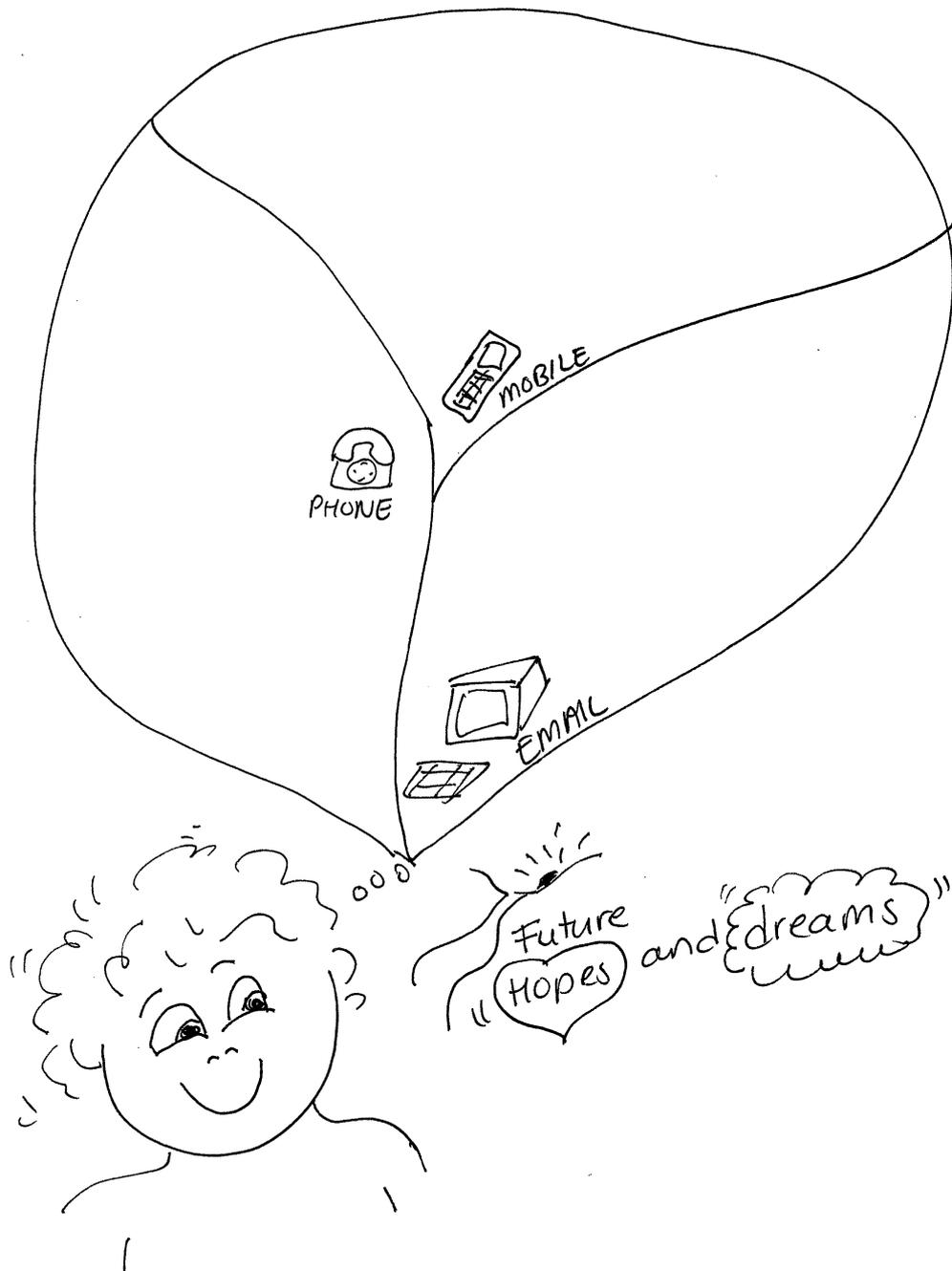
Other?

Appendix K (cont.) Examples of visual supports



Comments:

Appendix K (cont.) Examples of visual supports



Appendix L: Tables of Results with example quotes

Table 8 People-related facilitators with example quotes

Communication Partners	Example
Responsiveness of communication partners; timely and personal responses	PTR-A: “and you send them to G (friend) sometimes and that’s good cause she sends one back doesn’t she?” ACP-A: (AAC-user) “yes” ..(nods and smiles) PTR-A: “she does enjoy it..specially when someone replies. ACP-A: “yeah” (laughs).
Knowing comprehension of communication partner	ACP-C: “it’s best to use the whole words if no one understands, ...I prefer to write in the real sentence instead of the text language cause M (friend) doesn’t understand it.”
Timing (Com. Partner)	
Giving person time to construct their message	PTR-A: “let her work it out herself (referring to constructing message on device). She’ll make a mistake and then clear it and start again and she knows where she is.”
Predictable timing com. partner’s call	PTR-D: “every 2 nd week – 10-15 min..that’s his regular phone call with his (birth) parents... they ring us every fortnight at 7 o’ clock”
Taking time to listen	PTR-D: “and they always wait for him ‘anything else to say S?”
SMS –quick and short	ACP-B: “people can reply much quicker and short messages with a mobile”
SMS easier to understand than person’s speech.	PTR-A: “people really understand what she’s saying by text message” (referring to AAC-user with severely dysarthric speech)
Parent/primary caregiver	
<i>Facilitates use:</i> Provides training, inclusion and practice opportunities.	PTR-C: just sort of showed him how to do the basics and threw it at him and said here you go mate PTR-D: “Cause if I’m ever on the phone I always put it on speaker phone and then D has a bit of an earwig in and a comment here and there.. don’t you? (speaking to ACP-D)
Provides ‘communication options’(for AAC-user)	PTR-A: “I might make a suggestion and she says no..and we have to go through a whole lot of options before we find one.”
Parent gives literacy support	ACP-B: “So I would still need to check it and make sure he was putting in the right words here and there um because sometimes he does still come out with it back to front.”
Purchases/setup of equipment	PTR-C: “so that’s one reason why I got this (shows her phone) found out it had big things, so I got ACP-C one of the same”

Com. partner cont.	Example
Specialist skills; e.g. programming,	PTR-D: "I'm going to transfer all this stuff onto another page (referring to pages on the Dynavox) and put extra stuff in it... Look I've just changed about ten of his pages last night"
Parent being willing to learn	PTR-A; I've had to actually learn how to do it Interviewer: "and who's helped you to learn?" PTR-A; B (husband) and trial and error (laughs)
Parent - high expectations.	PTR-E; "yeah, because ACP-E has lots of original thoughts and ideas.. I mean I just know she can be expanded so much."
Parent having access to training and specialist support	PTR-C: "because I've done training with the vision impaired ...this is what we get taught, is how to manage our children...what it's like to have vision impaired person and daily living"
Paid carers	
Utilizes telecommunication use in contact with ACP	PTR-D: "with I (Carer) of course he's always texting him. They go back and forth ..I'm on my way'.. 'whatcha doing?'"
Having specialist skills	PTR-D: "but his carers have got those skills so that's good"
Provides training and support	ACP-E; "C helps me..she's my carer."
Friends/peers/siblings	
Having (typically developing) friends/contacts	PTR-A: "She likes ..her friends are the able bodied ones. There are some people she's been in school with, the able bodied, you know the mainstream and we keep in touch with some of them"
Friends/peers giving support	ACP-B: N (friend) has set him up a hotmail thing for him ACP-D: "friends showing you"
Siblings giving support	PTR-C: "and my daughter's starting to text him just to make sure that, you know, keep him using it. Texting, yeah so she's training him as well"
Friendship with fellow AAC-user (Mentor programme)	PTR-D: "How about with P (mentor).. go on, how do you feel when you talk for ages on the phone with P?" ACP -D: (points to) 'great' (on device) PTR-D: "yeah. cause P and him got the same language and they understand each other don't you?" ACP-D: (smiles)
Typically developing peer language model	PTR-B; "the whole thing about her communication has been around 'normal' teenagers and that has increased her vocabulary her understanding, her interest... And lots of different people her own age that haven't got a disability...and giving different experiences."

Table 9 Equipment-related facilitators, with example quotes.

Design/features	Example
Versatile nature of the mobile; 'contactable' anywhere, anytime.	PTR-C "yeah it is, but having the phone there, you know, like I say just text me anytime, but he's made friends with people around, in the mall, some of the people in the shops?...before I'd panic, I'd be following him around trying to duck behind, people...so yeah the independence that, you know, he said "what if I fall out of my chair?", "well, somebody can text me and say hey, ACP-C has fallen"
Appearance (mobile)	PTR-B: I think sometimes they get like. 'look I can do this on my phone it's really cool'. 'Can you do that on your phone?' I'm sure they all get together...'look at mine it can flip'. So I think peers have a big big influence."
Camera facility	PTR-B; "yes...It makes a big input too. I think he'll like it because it's quite a fun novelty thing to have. He can take a photo of N (friend) and have it consistently on his phone"
Font size	ACP-C (has visual impairment): "it's best to have a big, big, big screen and big letters that's what I would dream"
Key pad design (colour, size, layout, lighting)	ACP-C (with visual impairment): "I can see it through the day with the light but mines a bit brighter...my phone lights up and mums one doesn't light up good as this.... and the buttons being a lot bigger"
Access features	PTR-B; "this has got the wee raised bit (points to the middle of the key pad)...It shows you the 5 and that's for the blind people so they know where they are.
Ease of use (interface)	ACP-C: "well it's very easy to operate"
Text facility/written communication	PTR-B: "you've got it all written down and you don't forget like I do... so in that respect it could be quite good for kids to ...like B (ACP-B) that don't remember.
Screen size and colour	PTR-B: "For a starter the difference is size, a bigger screen, a more colourful screen ...If he's (ACP-B) sitting here (demonstrates) and he's texting, he can see something a bit more"
Speaker phone	PTR-B; "He manages the home phone but he always puts it on speaker phone, no matter what"
Phone to suit person	ACP-D (AAC-user) (points to communication board); 'Having the right phone'
Special Features; internet access on mobile, ring tones and music	ACP-B: " It (telephone) makes me happy... because of the ring tones."
Sufficient memory	ACP-C: "my computer is brand new so 4GB, over 4GB of memory, and it's so fast you just can't keep up with it"

Special equipment	Example
Cordless phone	ACP-C (good use of one hand/arm only): “I prefer to use the cordless phone cause it’s much easier than the normal phone I get sick of holding the receiver when I’m dialling the numbers”
Adapted mouse/switches	ACP-A: (Observed) Special joystick instead of standard mouse.
Touch screen	PTR-E: She can actually do all that (referring to touch screen). She hasn’t done it for a while because her hands are stiff and all that”
Headset	PTR-E: “yeah..the only way of H communicating with her is through the telephone (using skype and headset) so that H is hands free”
Speech generating device	Interviewer: “do you ever hold the phone to your Dynavox?” PTR-D: “yeah all the time.”
Vocabulary selection: a) stored phrases, b) page set up c) making all sorts of vocabulary available	a) PTR-A: “if you were at school and you suddenly wanted to send an email could you find someone and tell them?” ACP-A (AAC-user): (finds phrase) “I am going to write an email’ b) PTR-D: “we always have the phone on speaker phone and he always has this open (referring to ‘telephone’ page on Dynavox)... this page was made for them (birth parents)” PTR-D: “He looks at a page and he works it all out and you see him going through it and then he’s got it” c) PTR-D “I even changed the swear word page so when you open it up it goes whmmmm. and another goes shit.”
Key guard	“That (accessing mobile via device) would be helpful. Because you can use these ones can’t you (points to buttons/keyguard on Dynavox)”
Access IT	ACP-A: (Observed) allows transference of text from dynavox to computer, via infra-red signal.
Mounting of device	ACP-A & ACP-D: (Observed) Allows communication device to be mounted on to wheelchair for ready access.
Use of symbols (PCS)	PTR-A: “and the little pictures (symbols) help”
Appropriate wheelchair/table	PTR-C: “he cruises around (the Mall) cause he’s meet lots of people since he’s been in the electric chair.... he buzzes off around”
Contact list/special phone book	PTR-E: “when we first got this ...the thrill of being able to have all her phone numbers in her phonebook and being able to call someone without me standing there the whole time...her self esteem increases ‘hey look at me what I can do”
Access	Example
Having access at home	PTR-C; “yeah, we’ve got a router, and the laptop can go round the house anywhere and you can use skype on that”
Having access at school	PTR-A: “if you were at school and you suddenly wanted to send an email could you find someone and tell them? ACP-A: (finds phrase on dynavox) “I am going to write an email’

Access cont.	Example
Personal ownership	PTR-D; “This is the first year he’s (ACP-D) had his own phone”
Communication partner has access to similar equipment	PTR-C: “when he’s living in one place and I’m living in another, we can, you know send pictures and things like that”
Wheelchair access	ACP-A & ACP-D: (Observed): Two of the participants were wheelchair users and required suitable access to facilities
Cost/funding	
Funding of special equipment	PTR-C: “yes you can actually get help from the foundation for the Blind, yeah but then you can apply for funding”
Credit on phone	PTR-B; “he pays for his own. It comes out of his pocket money.”
Using same network as communication partner to save costs.	ACP -D(AAC-user): (S points to communication board) ‘having money’ ACP-C: “M (friend) doesn’t, he doesn’t have to pay much... M’s (friend) got 021, my uncle’s got 021 and everyone’s got 021, apart from my sister” PTR-C: (laughing) and most of my friends have got 021..so I thought no I’ll stick with the same one.

Table 10 Support/training related and ‘other’ facilitators with example quotes

Support/training	Example
Having access to specialist support	Interviewer; “Anything else that’s helped you?” ACP-B; “Speech Therapist”[at school} ACP-D; “People who know what to do”
Having access at school ‘Teacher’ other than parent	PTR-A: “they do texting at school” PTR-C: “It’s better if it comes from somebody else and that person has got better chance of teaching him.”
Other Facilitators	
Environment; having a quiet place	ACP-D (AAC-user) points to ‘a quiet space’ on communication board
Charity facilitating mentor programme	PTR-D: “and with P (friend who has CP and uses a Dynavox; introduced through Mentor Programme with a Disability Charity) they’re bent on those Dynavox’s..gee they’re funny.

Table 11 People-related barriers, with example quotes.

Communication Partners	Example
Limited responsiveness	PTR-A: “You know, they won’t always reply to her texts...she’s the one who makes the initial point of contact always...she might send six text messages over six weeks and then someone will say oh I’m sorry I’ve not been in touch...I’ve been busy or my phone ran out of money”
Unwanted/unknown responses	a) ACP-C: “and says “hello this is so and so speaking”, it’s like a survey or anything and don’t like getting surveys that’s why it’s annoying to get surveys everyday”
a) Sales people	b) ACP-C: “no I hate their answer phones that’s why...and that’s why I prefer to text them, instead of putting up with their, “hello we are not home at the moment please leave a message after the beep”
b) Answer phone	c) ACP-B: “well umm not when people put swear words in their texting...it makes me feel uncomfortable...cause people might swear on the phone.. and a bit unsure.”
c) Bully/swear text	d) ACP-D: “yeah, well for the email yeah viruses”
d) viruses	
Lack of verbal communication partners in (school)	PTR-E: “ACP-E has lots of friends who can’t communicate verbally and what happens to E’s communication if she spends too much time with them is she just starts talking to herself.”
People talking and not listening/waiting	Interviewer: So let’s talk about the normal phone, how does it make you feel? ACP-D: presses ‘sorry’ on dynavox. PTR-D: “cause sometimes when he has phone calls from people every week, they don’t always listen to him and they just keep talking. and he gets a bit..you get a bit cross sometimes don’t you? because they won’t listen to you. they go ya ya”. ACP-D: (points on communication board) ‘people not understanding me’
Difficulties understanding	
Limited contacts	PTR-B: “he (ACP-B) would probably not have someone exciting to email.”
	PTR-A: “The other students (at special unit) don’t text her (ACP-A)”
Communication partner not having equipment	PTR-E: “yeah..the only way of ACP-E communicating with her is through the telephone (using the skype) so that ACP-E is hands free but she (communication partner) doesn’t have the camera.
	PTR-B: “the only thing with email is that he (ACP-B) needs other people to email who have email.”
Parent/Primary Caregiver	Example
Restricts/limits use	PTR-B: “we’ve never thought about giving out ACP-B’s’s details. I give my details out for ACP-B. They contact me and I relate it to B.”
	PTR-A; “well if she does want to take a photograph then we take it for her, but we don’t umm offer it too often.”

Parent/carer cont.	Example
Limited time/patience/energy	<p>PTR-E: “M (father) hasn’t had the time (to do the programming).”</p> <p>PTR-B: “we got sick and tired of having to do it (helping ACP use the phone) ourselves”</p> <p>PTR-A: “you know she comes home at half past three and it’s afternoon tea time and I’ve got to get dinner on the table.. and we’re a busy household.”</p> <p>PTR-A: “the biggest thing is the time it takes and willingness on my part to make it happen for her. I’m happy to do that for her but not like a teenager would on and off the phone all the time for an hour you know. I don’t do give her an hour like that.”</p>
Limited knowledge	PTR-D: “I don’t know anything about the hotmail kind of thing”
Limited skills	<p>PTR-A: “if you press certain things something will come up but we don’t know where to find it (referring to ‘bling’ put on by sister).”</p> <p>PTR-A: “see this is where I get stuck. I’ve got the photos there but then not sure how to do it.”</p> <p>PTR-D: “I programme the dynavox but I don’t do computer”</p>
Reluctance to use services/technology	<p>PTR-B: “too much information... I think that’s my biggest fear with the internet... so that’s what frightens me about the internet that they can go too far”</p> <p>Interviewer: “what about the relay (speech to speech relay service)?”</p> <p>PTR-A: “I don’t know about that..that scares me ...It does sound very involved. I’d rather do it myself”</p>
Not wanting to ‘impose’ on communication partner	<p>PTR B: “the risk is then she’d be bothering people all the time. You know, you do try and limit it sometimes as to how often she sends people a text...she would send some people a text every day, even if they didn’t reply and you know some people don’t want a text everyday. It just puts pressure on them.”</p> <p>PTR-A: “The other students don’t text her but some of the carers do, they are very good. But again I have to be careful. They’re busy mothers with their own families.”</p>
Limited expectations	<p>PTR-A: “really she’ll only ever use the email for social things because of her inability to create new sentences.”</p> <p>PTR-E: “I think basically ACP-E’s learnt as much about Skype as she’s going to learn and that she knows what it’s for and she understands how it’s used. I think that’s as far as it will ever go.”</p>
Restricting vocabulary (AAC)	PTR-A: “shall we just tell S (interviewer) something that we have on our ‘communication board’... we call it ‘I want to do something else’..because we don’t say ‘bored’ in this house. (‘bored’ not on communication board).. we never say ‘bored’ because there’s always something else you can do. It’s like we won’t have ‘I’m depressed’ on her communication board.”

Parent/carer cont.	Example
Interference with AAC device	PTR-A: “if I say..’would you like me to do it?’ ..she says ‘no’ because she knows which button to press and which way she’s going to find what she wants and she knows that I might press the wrong one and then she has to clear it and start again or then she gives up, so I leave her to do it now.”
Paid Carers	Example
Carer ‘taking over the call	PTR-D: “he’s so reliant on others to actually hear it ringing and to answer it and to keep him in the loop, because I find sometimes people start having their little chat and they actually forget that this is S’s phone call and his talk”
Different expectations	PTR-D: “Just cause you (carer) think I (ACP) should to say it like that, doesn’t mean I’m going to.”
Not understanding communication/learning style of the ACP	PTR-E: “Carers are often not tuned in because it’s very obvious that it’s not their words..it’s not them”
Not responding in timely manner	PTR-D: “I just think you’ll find it hard to do anything with ACP-D in school because everyone has got their own way and even after all these years they still haven’t worked the way.”
Community/society	
ACP no longer ‘cute’	PTR-B: “but like I say as they get older they loose that cutie cute and it’s a whole different ball game. And it gets harder for them.”
Neighbors unsure	PTR-C: “they’re (neighbours) still sort of I think, unsure of him,
Lack of disability awareness	PTR-E: “that’s the thing with people with a disability they try to put everyone in the same box no matter what it’s for. It’s really frustrating.”
Policies and regulations of service providers	PTR-C; “we just got a new carer from xxx (National Charity for people with an Intellectual Disability), he starts tomorrow, so hope, the rules are from there that we are not allowed to trade cell phone numbers...there’s a big clause we have to sign, a thing to say we won’t exchange cell phone numbers, but to me it’s a safety issue if they’re late or we’re not home, you’ve got to use it”

Table 12 Equipment-related barriers with example quotes

Design/features	Example
Ring tone not loud enough	PTR-A: “if we’re in a busy place and we can’t hear it ringing she (ACP-A) gets me to check it every 10 min or so.”
Buttons too small	PTR-E: “It’s also manufacturers because mobiles are made for people who can use one finger to point but bigger keys”
Buttons not light up enough	PTR-B: “the numbers aren’t very bright on his either... you can’t really (see), so he’s up like this doing it (phone to face)”.
Letters on keys too small	PTR-B: “The numbers on it are so small, so I think he (ACP-B) had difficulty in using this. He just finds it too tricky. He’d rather not use it.”
Buttons hard to push	PTR-B: “ but he (ACP-B) just can’t you know and the buttons are really hard to push”
Layout; wrong colours	PTR-B: “there’s no segregation in here as to where it all cuts off, it all rolls into one”
Font too small	ACP-C: “and I looked at the letters (font size) and it was ‘no’ (shakes head) ACP-C: “I looked at this one (holds up his own phone) and said yes”
Insufficient memory (phone or computer)	ACP-C: “usually the space is the problem cause if, if we send too much messages, my space on the phone gets overloaded”
Phone too small	PTR-A: “think with the mobile they could make it a wee bit bigger.”
Screen size	ACP-E: “Half the time it’s hard with my eyes...it’s my eyes and my focus.”
Special Equipment	
Limited availability of specialized equipment	PTR-B: “It’s a pity they don’t make them (mobiles) for visually impaired.” PTR-C: “we’ve been trying to find one of those things (gestures to indicate headset) but you’ve got to have the right phone and the attachment and I’m like (shakes her head)... I can’t go to the shop, they haven’t got one or it’s the wrong plug...the plugging system.”
Vocabulary selection/page setup restrictive (of AAC device or software)	PTR-E: “but I feel the writing programme (computer software) is too basic. Because it says ‘Dear..’ Rather than doing that, ACP-E can just dictate what she wants to say instead of putting her in a big box.” PTR-E: “Because the more structure (referring to set phrases) you put in the more stunted it gets. The more you have these regulated replies for everything.” PTR-A: “you’ve got to be able to spell to be able to say something that’s not on the Dynavox . And although it’s got predictive text.. she would have difficulty reading those and distinguishing which one she wanted so she wouldn’t do it.”

Special equipment cont.	Example
Accent (USA) of device effects intelligibility	Interviewer: 'where should you have been today..is it on there? (points to Dynavox) ACP-A: responds by pressing button 'petanque' (American software mispronounces French word)
Slowness of scanning	PTR-D: "original thought, that's all very well, however, you put that into a scanning child and get them to choose every single, your original thought would just take forever"
Takes a long time to construct/type message.	PTR-D; "this is what you want to say but now you have to get the computer to go to that page, to go to that letter" ACP-C: "too much to type than texting.. cause typing just takes over two hours to type and I don't like that... it's easier to just text instead of type"
Difficult to respond quickly and flexibly with AAC device.	PTR-A: "If someone rings up and says I'll come and see you tomorrow she (ACP-A) can't tell them I've got something else on tomorrow. That makes her feel very confused and anxious." ACP-A: (confirms with loud vocalisations) PTR-A: "because she can't say; no I'm going out tomorrow... She's unable to expand on a question or comment."
Computer not converged on device	PTR-A: "Would it (your dream) be if you could use your Dynavox to make your cell phone work? Would that be helpful?... so you didn't have to fiddle around with the little buttons?" ACP-A: (nods with emphasis) "yeah"
Failure of 'Access IT'	ACP-A: (Observed) 'Access IT' allows transference of text from dynavox to computer, via infra-red signal but frequently fails to transfer every letter/number. This causes particular problems when it does not transfer a password accurately (as observed).
Speaker phone restricts privacy	PTR-A: "speaker phone's alright but sometimes I don't like to eaves drop into ACP-A's conversations though you know, there's very little privacy"
Phone book print too small.	ACP-C: "cause sometimes I can't read the, um...phonebook cause it's way too small to read"
Lack of contact list	PTR-B: "I think all the kids at school, if you wanted to set something up like in this system of getting them to do email between them they'd need a list of every body's numbers and emails,.. H doesn't have that either".
Head set falls off	PTR-A: "what about this, (points to head set) when we tried it out, what kept happening?" ACP-A: "off" PTR-A: "off that's right. It kept falling off."
Equipment failure/breakage	ACP-C: "woops the phone's not working, because the white phone's beginning to break down PTR-C: "sometimes (he) sort of drop the phone and a scramble round then he runs over it, those sort of, you know, mobility... not often your phone gets squashed by a wheelchair, or usually me standing on it cause he's dropped it"

Access	Example
Limited access to (specialized) equipment/computer	<p>PTR-E: "I mean once we get more programmes she'll be able to use those... we do actually want to get a jelly bean switch that is connected to turn on the computer"</p> <p>PTR-D: "because if your computer is over there again it's got to be when it suits everybody else"</p>
Unable to access standard equipment effectively/independently	<p>PTR-E: "the conversation isn't as fluent because (when) I'm holding the phone (standard equipment) to ACP-E's ear and she keeps turning her head all the time she's not always hearing the conversation at the other end and it gets very stunted. You know it doesn't flow like it does on the computer (with headset).</p> <p>ACP-A: (points to word on communication board) 'frustrated'</p> <p>PTR-A: is it because you want to text when I'm not ready?</p> <p>ACP-A: (no response)</p> <p>PTR-A: is it because you can't do it yourself?</p> <p>ACP-A: "yes"</p> <p>PTR-A: "even with the computer I can't just plug it into the computer and say use it, he still has to have special plugs and everything... and a scanner"</p> <p>PTR-D: "He's (ACP-D) only had his phone this year."</p>
Not owned phone long	
Cost/funding	Examples
Cost of special features	<p>PTR-A: "we sent a photo to B (friend of ACP-A) once when on holiday. It does cost money so we don't do it too often."</p>
Running out of credit on phone	<p>PTR-B: "well he (ACP-B) was certainly going through his share of the free texting (text payment scheme) cause he'd run out, so must have been doing his monthly 500".</p> <p>ACP-C: "I always have to put credit on my phone when I run out... because if, well you (run out of credit), you can get replies but you can't text them back."</p>
Com. Partner different network	<p>PTR-C: "my daughter's got an 027 and she keeps telling us to buy an 027, you know and she does the text 2000 and she gets annoyed because she has to pay to text us (PTR-C and ACP-C).</p>
Other people using credit	<p>ACP-B: "I get very cross when people use up my money"</p>
Not aware of plans	<p>PTR-C: "no I just do, I put \$20 in. I mean we're still learning about those things"</p>
Expense of special equipment/mod's	<p>PTR-C: "I think it's about \$500 to get (the mobile) adapted (for visually impaired) phone provision"</p>
Expense of getting to spec. training/facility	<p>PTR-D: "and that's huge miles to be clocking up on the van as well...because somebody has got to pay for the diesel for that van. .. there is a limit to how much I can pull out of my pocket."</p>

Table 13 Training/support-related barriers with example quotes

Training/support	Example
ACP needs further training	PTR-A: “ACP-A doesn’t actually know how to use the phone, which buttons to press..do you? ACP-A: (shakes head no).
Needs trainer other than PTR	PTR-B: “they don’t tend to listen to their parents very well... It’s better if it comes from somebody else and that person has got better chance of teaching him. If I try and teach him here, it’s like oh mum, yeah yeah I got it Mum”
ACP Lack of knowledge re; services e.g. relay	Interviewer: (Listing things that might be facilitators) ‘having a relay system’ ACP-D: “huh?” Therapist; “I don’t know we’ll find out (replying to SR’s ‘question’ what is relay)”
Long time to get to spec training/facility Requires 1:1 support (lack of support)	PTR-D: I had thought about going over to B (Special centre for accessing com training)... which is good but it’s a long way from ACP-D (home) and it’s almost three quarters of an hour from here” PTR-A: I can’t do anything else while she (ACP-A) has my full attention on those things..she’ll always need someone who is able to help” ACP-D: points on communication board ‘someone not having time to help’
School: a) funding	PTR-C: “we should be getting (support) from the Foundation for the Blind, but (school) won’t pay for it.
b) Limited training/use opportunities	PTR-E: “she’s not doing email at school as far as I’m aware. It’s letter writing, putting the letter in the envelope and taking it down to the post office.” ACP-B: “We don’t have email at school”
c) Different expectations	PTR-D: “To get him to like the computer it hasn’t been easy whereas sometimes at school I think they’ve made it more difficult than easy. People have their expectations of what they want to happen whereas he doesn’t like that...Just cause you think I should to say it like that, doesn’t mean I’m going to.”
d) Not enough time	ACP-E: “no it’s that ..during the day (at school) I don’t have enough time
e) Lack of specialized support	Interviewer: “Have you ever had help in terms of using the phone from Speech Therapy, or Occupational Therapy or Physiotherapy? ACP-B: “ no, no and no”
f) Lack of privacy/ less personal/less enjoyable	PTR-A: “mostly it (sending emails) is at school. It’s not quite so personal for her I think.” PTR-D: “when you do emails at school how do you feel?” ACP-D: (presses on Dynavox) ‘Angry’
g) Different learning styles; home - school	PTR-E: You see at school I think it’s a totally different style of learning language. Because basically you’re setting up a form..like with the letter writing you’re setting up a formula for the way you should do things, but what’s happened to spontaneous communication and your own ideas and not necessarily having a structure for the way you have to speak to somebody.”

