Sounds of Smiles: Perspectives on Telecommunications Access Methods of People with Complex Communication Needs

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Declaration

I declare that this thesis does not contain, without acknowledgement, any material previously submitted and accepted for the award of any degree or diploma in any tertiary institution; and does not contain any materials previously written or published by another person, except where due reference is made in the text of the thesis.

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Abstract

People with Complex Communication Needs (CCN) require improved methods of accessing telecommunications, given the communication barriers they face, to participate fully in society. This research explores the types of telecommunications access methods adults with CCN use and report to be useful, as well as their perspectives of the usefulness of a Video-Assisted Speech-to-Speech Relay (VAS) service. The research used a mixed methods design employing both quantitative and qualitative approaches. An online survey was undertaken, which attracted 13 respondents with varying disabilities, including Cerebral Palsy, Dystonia and Traumatic Brain Injury. The respondents reside in Australia, Ireland, the United Kingdom and the United States. Over half of the respondents have a tertiary or post-graduate education. Survey respondents were also invited to participate in an online focus group, which was undertaken to provide further insight into the experiences of survey participants. Six of the survey respondents participated in the online focus group. A comparative analysis was conducted on the data collected to gain a greater understanding of user perspectives on the usefulness of these telecommunications access methods. The analysis of the research draws on Bourdieu's theory of society, and more specifically, his concepts of habitus, field and capital. This thesis then applies Bourdieu's theory of society to post-modern perspectives on disability to examine the importance of social participation based on the experiences of people with CCN who use telecommunications in an effort to increase their social and cultural power, and gain greater control over their lives. People choose the communication strategy that will attract the most capital (Bourdieu, 1986) and this is apparent from the findings with the respondents reporting they use a range of telecommunications access methods in their communication. The respondents indicated they use a number of communication strategies in different interactions; aided Augmentative and Alternative Communication (AAC) is not always their primary communication method.

There are three main findings from this study. First, all respondents use text-based telecommunications, for example email, SMS, instant messaging and social networking websites. Second, all respondents use video-based telecommunications, such as Skype, predominantly to communicate with family and friends, adding weight to the position that people with CCN use the appropriate communication strategies for participating in their various social fields, depending on which their habitus suggests will yield the highest return of capital. Third, the respondents express a perception that VAS could potentially enhance their access to telecommunications, especially to communicate with unfamiliar communication partners.

This research suggests that people with CCN are using a variety of telecommunications access methods to participate in society and to accumulate social capital. Without these technologies, their ability to accumulate social capital is limited. By understanding their struggle in their social fields, research can start to answer the question of what support can be provided to help them in this struggle to maintain and accumulate power, and so gain greater control in their own lives. The research also reveals several areas for further research into the enhancement of communication strategies using telecommunications to increase the return of social capital available to people with CCN.

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1 Introduction

An essential part of participating in and belonging to a community is the ability to communicate (Collier, Mcghie-Richmond, & Selfa, 2010); this is an integral aspect of the human rights charter in The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2010). The Augmentative and Alternative Communication (AAC) field emerged in response to the needs of people with Complex Communication Needs (CCN) who are unable to use speech for everyday communication and may not be able to benefit from traditional speech therapy given their limited lack of functional speech (Alant, Bornman, & Lloyd, 2006). The term AAC means "a compilation of methods and technology designed to supplement spoken communication for people with limited speech or language skills" (Wilkinson & Hennig, 2007, p. 58). Originally, the AAC field was concerned with the physical use of the AAC technology, but in recent years, has expanded into the cognitive and social sciences (Alant, et al., 2006).

People with CCN are increasingly participating in society (Blackstone, Williams, & Wilkins, 2007; Collier, et al., 2010; McNaughton & Bryen, 2007) through taking up socially-valued roles such as parents, lovers and productive workers (Bryen, 2008). The literature discusses the barriers arising from communication difficulties that reduce the power of individuals with CCN to participate fully in society (Bryen, 2008; DeRuyter, McNaughton, Caves, Bryen, & Williams, 2007; Eardley, Bruce, & Goggin, 2009; McNaughton & Bryen, 2007). DeRuyter et al. (2007) suggest people with CCN require improved access to telecommunications to enhance their communication and therefore their participation in society.

Social relationships are increasingly being maintained through the use of telecommunications (Notley & Foth, 2007). Eardley, Bruce and Goggin (2009) summarise research suggesting there are economic and social benefits that flow to the community when individuals have access to telecommunications. These include improved personal safety, enhanced social

networks, increased access to local and international communities, greater participation in self-directed learning and more efficient government service delivery. However, access to telecommunications has become essential for participation (Owens, 2006; Sengara, 2009) and new telecommunications technology is often not as accessible to people with disabilities as it is to the general community (Eardley, et al., 2009; Goggin & Newell, 2007). In an attempt to overcome these barriers, Speech-to-Speech Relay was introduced in Australia under the Universal Service Obligation (USO) and has been operating since 2000 (ACMA, 2010b).

Speech-to-Speech Relay (SSR) is a service that assists with telephone conversations between two parties, one of whom has CCN. The person with CCN can choose to communicate using their natural speech or using an AAC speech-generating device. A trained Relay Officer (RO) remains on the line to assist when communication difficulties occur. The introduction of Video-Assisted Speech-to-Speech Relay (VAS) is seen as a move to modernise SSR (COAT, 2011). This technology also involves making a phone call over a standard telephone line and has a Relay Officer to assist with the communication breakdowns. However, in addition, VAS allows people with CCN to employ multiple communication modes during telephone calls by using internet instant messaging and video service, such as Skype. All three parties can hear and speak to each other, but the person with CCN and the Relay Officer can use the video and text facilities to help overcome communication breakdowns.

This research explores the telecommunications access methods that assist to empower individuals with CCN to participate fully in society. The thesis draws on Bourdieu's theory of society and post-modern perspectives on disability. As Bourdieu (1986) suggests, social capital is accumulated through a variety of communication strategies. Accordingly, Notley and Foth (2007) argue the ways social capital is accumulated are changing as increasingly people use telecommunications technology to maintain their social relationships. Similarly, people with disabilities are benefiting from having access to telecommunications, reducing

isolation and improving social development and obtaining a sense of control over one's own life (Tilley, Hills, Bruce, & Meyers, 2002). In doing so, people with CCN are increasingly participating in their communities in socially valued roles (Bryen, 2008).

The design of the project methodology involved three iterations before reaching the current one. The first, influenced by the researcher's Computer and Information Science background, began with research into developing an alternative vocabulary access system for people with CCN. The second took on a social science research approach with the aim of investigating user perspectives on introducing VAS to support people with CCN in using the telephone. However, the number of participants recruited was low making this line of enquiry difficult to pursue. One possible explanation for the low response to recruitment might have been that potential participants perceived the project as too demanding. In an effort to inform the development of an appropriate methodology suitable for the target audience, the researcher sought feedback on the proposed methodology from attendees at the 2010 international bi-annual conference of the International Society for Augmentative and Alternative Communication (ISAAC) in Barcelona. On the basis of this feedback, a decision was made to modify the methodology to reduce the physical demands on participants. The final iteration of the design reflects this decision and thus focuses on an investigation of the telecommunications access methods people with CCN use, their perspectives on those methods and their perspectives of the utility of VAS.

This thesis draws on Bourdieu's theory of society, his concepts of habitus, field and capital, and post-modern perspectives on disability to examine the importance of social participation based on the experiences of people with CCN who use telecommunications in an effort to increase their social and cultural power, and thus gain greater control over their lives. This research aims to explore the current telecommunications access methods people with CCN use, their perspectives on those methods and the utility of VAS, and include a comparative

analysis examining these perspectives. In addition, the project aims to build a framework for future developments of telecommunications for people with CCN and highlight areas requiring future research. The research used a mixed methods design employing both quantitative and qualitative approaches by utilizing an online survey and an online focus group. The online survey provided the researcher with the main research data, whilst the online focus group provided the opportunity for the researcher to explore issues from the survey should they arise.

The chapters of the thesis are organised as follows. The Literature Review (Chapter 2) provides a brief overview of theories of disability and an extended theoretical model drawing on the work of Pierre Bourdieu, a French sociologist. Furthermore, the literature review explores telecommunications for people with CCN and presents evidence to support the argument that participation in 21st century society requires access to telecommunications. Video-Assisted Speech-to-Speech Relay (VAS), an alternative access method of telecommunications is also discussed, drawing on the literature surrounding relay services globally and research on communication assistants for people with CCN.

The first section of the Methodology (Chapter 3) presents the research questions and discusses the methodological issues of the research based on the literature. The four phases of the project are also presented.

A summary of the findings of the online survey and focus group is presented in the Results section (Chapter 4). This chapter begins with an overview of the survey responses, followed by the demographic information about the survey respondents and the online focus group participants. The findings from descriptive analysis of responses to the survey follow.

The Discussion section (Chapter 5) provides a detailed discussion and interpretation of the results of the research, viewing them through a Bourdieuian lens, and comparing and contrasting the results with the literature.

The concluding chapter (Chapter 6) explores the implications of the findings, discusses the limitations of the research and makes recommendations for further research.

2 Literature Review

2.1 Introduction

This chapter begins with a brief overview of theories of disability that feature in the literature, with a particular focus on postmodern accounts of disability. This overview also provides an extended theoretical model that has been developed drawing on the work of Pierre Bourdieu, a French sociologist, in acknowledging that the body and society are interwoven.

The second part of this chapter reviews the literature focusing on telecommunications for people with CCN and presents evidence to support the argument that participation in 21st century society requires access to telecommunications. It argues that while technology has helped remove some barriers to access it has also introduced new ones. The literature review discusses the "digital divide", which is brought about by some of these barriers. Initiatives to address some of these barriers are discussed, including web accessibility, Speech-to-Speech Relay (SSR) Services and the concept of a Universal Service Obligation.

The third section discusses Video-Assisted Speech-to-Speech Relay (VAS) as an alternative access method of telecommunications for people with CCN drawing inspiration from the concept of the Video Relay Service for the Deaf community. As VAS is only in the early stages of implementation, there is little research on the efficacy of such a service. Additionally, research suggests people with CCN use multiple modes of communications (Alant, et al., 2006; Blackstone, et al., 2007). The literature addresses the efficacy of communication assistants who work with people with CCN, assisting them to participate in their communities (Collier, et al., 2010). This section discusses the role of communication assistants, and argues they serve a similar function to that of VAS Relay Officers. This discussion provides some insight into the role and importance of Relay Officers.

This research adopts a postmodern theorisation of disability to examine the impact that access to telecommunications for people with CCN has upon their participation in society. The analysis of the research draws on Bourdieu's theory of society, and more specifically, his concepts of habitus, field and capital. There are differing views regarding whether Bourdieu's concepts are based on a post-structuralist or postmodernist approach (e.g., Harrison, 1993), but such analysis is beyond the scope of this study. It is argued that Bourdieu's theories are particularly relevant to this study, since many researchers use his work in their exploration of postmodern understandings of disability (Björnsdóttir & Jóhannesson, 2009; Edwards & Imrie, 2003; Simmons, Blackmore, & Bayliss, 2008). This thesis therefore draws on these theories to examine the importance of social participation based on the experiences of people with CCN. The focus is on individuals with CCN who use telecommunications in an effort to increase their social and cultural power, and gain greater control over their lives.

2.2   Models of Disability

Disability related research undertaken by sociologists and social researchers since the early twentieth century have predominantly focused on either the disadvantages resulting from biological impairments or socially-constructed discrimination (Barnes, 2003; Oliver, 1990; Shakespeare, 2006). The medical model of disability was one of the first models to emerge in the early part of the twentieth century. This model focuses on a person's impairment with the aim being to minimise the impairment so the individual can live a "near normal" life (Thomas, 2002, p. 41). Within this model, an individual's impairment, be it physical, sensory or mental, is regarded as the cause of the disability (Barnes, 2003). People with a disability are often referred to as "victims" or "invalids", or people in need of care, and this has led to the view that people with disabilities need to be "cured" and rehabilitated; the assumption being that medical intervention is required (Barnes, Mercer, & Shakespeare, 2010, p. 161). In the late twentieth century, the social model of disability became more widely adopted. The social model aims to move the focus away from the impairment of people with disabilities to

instead focus on the barriers—physical, cultural and social—which exclude or disadvantage them (Barnes, 2003).

Oliver (1996, p. 17) claims "…we must not assume that models in general and the social model of disability in particular can do everything; that it can explain disability in totality". Raghavendra, Bornman, Granlund and Björck-Åkesson (2007, p. 349) appear to support this notion stating disability, "is a multi-dimensional phenomenon that arises out of the interaction between features of an individual's health status and his or her physical, social, and attitudinal environments". Departing from the biological and cultural models, postmodern understandings of disability have emerged in more recent times, recognising the body and society are entwined (Edwards & Imrie, 2003; Hughes, 2002). Simmons, Blackmore and Bayliss (2008) illustrate how these postmodern theories can reveal new ways of understanding of the lives of people with disabilities providing a richer insight. They do this through presenting two case studies employing a different postmodern approach for each. The first case draws on a Deleuzo-Guattarain perspective and the second using a Bourdieuian approach. Simmons et al. (2008) suggest these approaches highlight the dynamic notions of disability and social inequality that are experienced in the lives of people with disabilities.

2.3   Habitus, Field and Capital

Pierre Bourdieu created a sociological theory of practice utilising the concepts of habitus (predisposition), field (interrelationships among players) and capital (social, cultural and economic) (Webb, Schirato, & Danaher, 2002). The theory is useful for exploring the social and cultural factors contributing to inequalities in society (Edwards & Imrie, 2003). Bourdieu argues that people compete for social capital in various areas of their lives and these areas he refers to as social fields, which are said to be hierarchical in nature (Webb, et al., 2002).

Bourdieu and Wacquant (1992) argue people use their habitus and various communication strategies to improve their social position. Habitus is described as people having

dispositions—perceptions, thoughts and behaviours—that are continuously being shaped in response to structures around them (e.g. society, family and education) and their interactions with other individuals within social fields (Webb, et al., 2002). In the same way, learning a skill involves internalising information to the point where the activity becomes automatic and unconscious, a person's habitus causes them to act unconsciously in a way that has a higher probability of yielding a favourable result (Webb, et al., 2002). Consequently, it is argued that by exploring the habitus of people with CCN and the habitus of the various social fields in which they participate, it is possible to gain greater insight to the communication barriers they face.

Bourdieu (1986) in "The Forms of Capital" describes three types of capital: economic, cultural and social. Economic capital refers to any resource that can be converted into financial capital. Cultural capital is the tangible and intangible benefit people accumulate in their lifetime giving them greater status in society, such as knowledge, skills, education, advantages and material wealth. Bourdieu (1986) describes social capital as "… the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition" (Bourdieu, 1986, p. 51). In other words, social capital primarily relates to personal relationships and social networks. Bourdieu (1986, p. 249) claims people need to continually work at socialising to accumulate social capital, while also acknowledging the interdependence of the other forms of capital. Bourdieu (1986) further notes the total of a person's social capital can be determined by the number of relationships within their social network and the amount of reliable acquaintances they have.

Social fields are socially constructed domains that are hierarchical and dynamic by nature, within which individuals pursue their desires through continual positioning and striving for power (Bourdieu & Wacquant, 1992; Webb, et al., 2002). Each field has its own mechanism

for governing the distribution of capital and it contains continuous conflict and competition, which Bourdieu labels "struggle" (Bourdieu & Wacquant, 1992, p. 17). He goes on to suggest people gain capital chiefly through communication and self-presentation, and their degree of success will directly affect the continuing struggle they face in positioning themselves in the field. Abilities are valued highly in social fields and therefore the habitus of many social fields devalues the abilities of people with a disability and erects additional barriers to gaining various forms of capital, and ultimately power (Edwards & Imrie, 2003).

Edwards and Imrie (2003) suggest Bourdieu's concept of habitus assists in the understanding of the social inequalities experienced by people with disabilities. Their research has explored the structured social inequalities from a cultural capital perspective and drawing on the experiences expressed by people with various mobility and vision disabilities. Applying a Bourdieuian lens to their analysis, Edwards and Imrie (2003) argue that the body, through bodily functions, both interrelates with and is influenced by the social and physical environment. They suggest people with disabilities have to struggle in the physical environment (e.g. access to facilities) as well as with the reactions of people whose behaviour is influenced by their individual and collective habitus.

In particular, Edwards and Imrie (2003) assert that one of the barriers people with communication disabilities face is the response they receive from other people; their abilities are less valued as their communication modes are different and therefore not as socially acceptable. Responses by these individuals to people with CCN is automatically evoked through their habitus, and can leave the person with CCN feeling as though they are being ignored or devalued. In situations where discussions and negotiations are taking place, the person possessing the most fluent, coherent and well-structured communication will tend to attract more capital than someone who has communication difficulties. As Edwards and Imrie explain, a person with a communication impairment in a meeting setting is likely to be at a

disadvantage, possessing less cultural and social capital compared to their counterparts, to influence the outcomes of the meeting.

While researchers such as Edwards and Imrie (2003) focus on Bourdieu's concept of cultural capital in their data analysis, others have focussed on the need for increasing social capital, thus increasing social networks. Potts (2005) suggests people use their social networks as a source of job opportunities and acknowledges people with disabilities generally have less capability to accumulate social capital, and thus have smaller social networks. Potts goes on to argue more support should be provided to jobseekers with disabilities to increase their social capital to enhance employment opportunities. To enable people with CCN to increase their social networks, Blackstone et al. (2007) assert that they require access to the appropriate communication technology and strategies. Likewise, Balandin, Berg and Waller (2006) reporting on the loneliness of older people with cerebral palsy, also highlight the need for increased support for these people to improve their social networks and thus their quality of life.

Scholars have applied a Bourdieuian understanding to investigate the dynamic notions of disability and social inequality people with disabilities experience in their lives (Björnsdóttir & Jóhannesson, 2009; Edwards & Imrie, 2003; Simmons, et al., 2008). This thesis further explores the experience of people with CCN using telecommunications using the theoretical lens of Bourdieu's concepts of habitus, field and capital, with a particular focus on social capital.

2.4   Life challenges for people with CCN

Alant et al. (2006) state the Augmentative and Alternative Communication (AAC) field has emerged in response to the need of people with CCN to be able to participate in their community. They explain that people with CCN may not be able to benefit from traditional speech therapy due to having little or no functional speech. The field was originally

concerned with the physical use of AAC, but has expanded in recent years into the field of cognitive and social sciences with growing interest in research exploring social interaction and communication strategies, which include social networks (Alant, et al., 2006). The AAC field has thus evolved to address the:

> … complicated interrelationship between the features of the AAC technology, the individual's physical (motor, sensory, perceptual) ability, cognitive/linguistic skills, and device users and their communication partners' abilities to interact and communicate (Higginbotham, Shane, Russell, & Caves, 2007, p. 243)

Collier et al. (2010) assert that the ability to communicate is an essential part of belonging to and participating in a community; the ability to foster relationships and to share with others. They further state the AAC literature has well documented the importance of community participation and developing social networks. The United Nations Convention on the Rights of Persons with Disabilities similarly acknowledges that community inclusion and participation are fundamental human rights (United Nations, 2010). Likewise, Bourdieu (1990) suggests communication is a necessary ability to participate in the community—what he refers to as the social field—asserting the act of developing social networks is the act of accumulating social capital.

The communication challenges faced by people with CCN and the significant barriers they experience when communicating with people within their communities are well documented (Collier, et al., 2010; DeRuyter, et al., 2007; McNaughton, Symons, Light, & Parsons, 2006; Rackensperger, Krezman, Mcnaughton, Williams, & D'Silva, 2005). Collier et al. (2010) summarise research where people with CCN report they have experienced many challenges in communicating with others who are unfamiliar with their communication methods. These challenges include the communication partner dismissing them, using closed questions to dominate the conversation, directing the conversation past them to their companion/s and often not using language that respects the person's intellectual capabilities. As a result, Collier et al. (2010) suggest these communication experiences can cause negative feelings from

loneliness to discrimination and can impact on the mental health of the person with CCN. Such barriers to communication have been found to also impact on the employment opportunities for people with CCN.

Most adults with CCN want to be empowered in their daily lives, in managing their support services and participating in society through education, employment and social networks (Bryen, 2008). Research undertaken by McNaughton, Light and Arnold (2002), involving eight full time employed individuals who have cerebral palsy and who use AAC, found that people with CCN who gain employment find empowerment to make decisions about their lives and gain self esteem and confidence, through having extra financial capital and " ... identified social networks ... as critical resources when seeking employment" (p. 72). Similarly, Potts (2005) asserts a social network is an important resource for job seekers in finding employment. These social networks are what Bourdieu (1986) refers to as social capital. However, people with severe and multiple disabilities are the least likely to undertake tertiary education (Wagner, Newman, Cameto, Garza, & Levine, 2005) and thus the employment rate for those with CCN is lower than other major disability groups (McNaughton & Bryen, 2007).

Research has identified that meaningful participation requires " ... gaining and maintaining access to the Information Society" (DeRuyter, et al., 2007, p. 268), and researchers have called for AAC designs to incorporate facilities for telecommunications (McNaughton & Bryen, 2007; Nguyen, Garrett, Downing, Walker, & Hobbs, 2008), to reduce barriers to participation in the information society (DeRuyter, et al., 2007). New technology strategies are required to ensure AAC devices gain and maintain interoperability with telecommunications with the rapid developments in mainstream technology (Blackstone, et al., 2007; DeRuyter, et al., 2007). People with CCN therefore require access to appropriate

technologies to be able to participate in society; without these technologies, their ability to accumulate social capital is limited.

Adequate language and digital literacy are required to participate in the information society (Migliorino, 2011). Digital literacy has evolved from traditional literacy—reading and writing skills—to encompass the skills required to access and manage online information (Bulfin & North, 2007; Poore, 2011). Research has reported traditional literacy can be challenging for people with CCN (Erickson & Sachse, 2010; Van Balkom & Verhoeven, 2010). Furthermore, the estimated speed of generating messages using a speech generating device is between 10 and 20 words per minute, depending on the person, type of the device and the situation (Nguyen, et al., 2008; Ratcliff, Sutton, & Lehman, 2009). Given the difficulties people with CCN experience with regards to literacy and the speed of generating a message, communicating with an AAC device via telephone can be tremendously slow and tiresome for both partners of the call (Nguyen, et al., 2008).

Bryen (2008) highlights the need to develop methods for improved access to vocabulary, which is specific to the social fields in which people with CCN participate. Bourdieu (1990) suggests using the right vocabulary in the context of a particular social field attracts greater capital. This highlights the need for effective methods for people with CCN to generate messages for communication in a wide variety of social settings.

The literature discussed above supports the view that the purpose of the AAC field is to enhance the communication strategies of people with CCN so they can participate in their communities through communication. The AAC field has recognised the importance of literacy and the ability to generate textual communication for participation in the community, for both face to face and telecommunication interactions. As DeRuyter et al. (2007) argue, people with CCN require more than face to face communication, they also require access to telecommunications in order to fully participate in their communities. In Bourdieuian terms,

this is the need for communication to participate and position oneself in the social field (Bourdieu, 1986).

2.5 Telecommunications access methods

Telecommunications services such as Internet access and mobile phones have become essential for participation in society (Owens, 2006; Sengara, 2009). According to the International Telecommunications Union (ITU) (2010), in the past five years, the number of people who access the Internet has doubled and in the three years since 2007, the usage of SMS (Short Message Service) globally has tripled, with an estimated 6.1 trillion messages being sent in 2010. For the year 2010, ITU (2011) reports that in the developed world, mobile phone subscriptions reached 114 subscriptions per 100 inhabitants.

Furthermore, telecommunications are used to accumulate social capital through maintaining social networks. As Bourdieu (1986) suggests, social capital is accumulated through a variety of communication strategies. Accordingly, Notley and Foth (2007) argue that the ways social capital is accumulated are changing as more people use telecommunications technology to maintain their social relationships. Eardley et al. (2009) explain how the mobile phone has become a tool for generating social capital through ownership, usage and extending social networks.

Similarly, people with disabilities are benefiting from having access to telecommunications, reducing isolation and improving social development and gaining a sense of control over one's own life (Tilley, et al., 2002). Research by Balandin et al. (2006) reveals people with cerebral palsy are likely to experience more loneliness than people without disabilities and recommends an increase in support in relationship building to enable them to minimise loneliness. Expanding on this, Cooper, Balandin and Trembath (2009) in their small scale research study exploring the loneliness experience of young adults with cerebral palsy who use AAC, highlight the importance of young people having adequate access to

communication and the importance of individual access to a range of telecommunication options. They also note the importance of having adequate literacy to be able to communicate with their peers throughout their lives.

New developments in technology are often seen as reducing barriers to participation. However, this is often not the case (Eardley, et al., 2009; Goggin & Newell, 2007). Although there are some people with disabilities who are technology "savvy" and make effective use of the latest technology, the usage of broadband Internet is higher in the general population than amongst the population with disabilities (Morsillo, 2011). Affordability, accessibility and availability of telecommunications have also become factors impacting on social participation (Goggin & Newell, 2003; Nguyen, et al., 2008; Notley & Foth, 2007; Owens, 2006; Sengara, 2009). Nguyen et al. (2004) argue that such factors have been longstanding issues for people with disabilities.

In relation to accessibility, Eardley et al. (2009) state that new technologies can sometimes create barriers to telecommunications for people with disabilities. For example, Simpson (2009) points out the ability to use a phone is an ingrained part of participating in our culture, yet " ... those with disabilities involving hearing, speech and vision may encounter numerous barriers if phone systems are not set up to accommodate to the needs of people with disabilities". Similarly, Owens (2006) identifies several barriers including economic and affordability issues, poor design for access by people with physical or cognitive impairment and insufficient support for end users.

Morsillo and Ciavarra (2010) point out that by signing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Australia has committed to ensuring people with disabilities have access to telecommunications services such as phone, Internet and emergency services. Although some of the barriers to access to telecommunications can be addressed through adaptive technology, Eardley et al. (2009) suggest these technologies are

often too expensive or potential users might be unaware of their existence or availability. Further, the authors note that people with disabilities are more likely to be financially disadvantaged than the average population in developed countries due to lower employment opportunities and extra costs associated with their disabilities. Such economic barriers have an impact on the affordability of the adaptive technology required by people with disabilities. Thus, Eardley et al. (2009, p. 10) suggest the "digital divide" continues to grow with the growth of Internet access and the increasing number of disadvantaged, including those with disabilities. Elman (2001) appears to agree, suggesting that as many public services are increasingly being delivered online, people with limited or no access are marginalised even further. Elman argues more attention must therefore be paid to the design of websites to prevent some of the barriers caused by website inaccessibility.

With increased services becoming available online (Elman, 2001) and people with CCN increasingly participating in socially-valued roles (Bryen, 2008), website accessibility has become increasingly important for web designers and developers to incorporate into their practice. The Web Accessibility Initiative (WAI)[1] has increased the awareness of the needs and issues surrounding web accessibility to web designers and developers through the publication of guidelines and recommendations focussing on web content, authoring tools and user agent accessibility. However, the consortium does not have the power to force people to adhere to these guidelines, hence inaccessible websites continue to be a major problem experienced by people with disabilities (Goggin & Newell, 2003).

In a similar vein, DeRuyter (2007) calls for developers and manufacturers of assistive technology, including AAC, to ensure their products are inter-connectable with telecommunications technology. Nguyen, et al. (2008) point out disability lobby groups and organisations have pushed for mobile phone technology developers and manufacturers to

[1]An international consortium of organizations (including commercial, educational and governmental entities) and individuals with an interest in web accessibility

adopt "Design for All" principles. The industry has been pressured by the regulatory environment to adopt these principles to ensure everyone can use their products, including the elderly and users with disabilities. These principles state where manufacturers cannot ensure a Design for All solution, they should enable interfaces that can connect to assistive technology. Similarly Wood (2010) explains that developers of online social network applications and 3D virtual worlds, which are of a dynamic nature and incorporate rich media, face the challenge of making participation accessible to all. Wood argues such accessibility is achievable by following universal design principles.

Another initiative aimed at assisting to make telecommunications accessible for all is the Universal Service Obligation (USO). Alleman, Rappoport and Banerjee (2010) discuss the concept of a USO, which was first a part of a marketing campaign of Bell Systems in the 1970s to offer subsidies on fix-line telephones in the USA. The concept was adopted throughout the world with the precise definition varying between countries. They go on to argue that the definition of USO should move from being narrowly defined and technology-based, that is subsidy for telephone, to one that encompasses all and newly developed communication technologies and services. According to the Australian Communications and Media Authority (ACMA) (2010c), there is only one nominated USO provider in Australia (Telstra) at this point in time. Under USO, the provider has the responsibility "… to ensure that standard telephone services, payphones and prescribed carriage services are reasonably accessible to all people in Australia on an equitable basis". The Australian Government acknowledges that accessing telecommunications has become more than just access to the standard fixed line telephone and, in May 2010 Senator Conroy, Minister for Broadband, Communications and the Digital Economy, announced that the Australian Government would conduct a major review of telecommunications services. This review includes an investigation of the need for potential improvements and future developments for the National Relay

Service and also includes an enquiry into the technical feasibility of providing an SMS emergency service (Conroy, 2010).

2.6   The Australian National Relay Service

The Australian National Relay Service (NRS) is a service provided twenty-four hours a day, seven days per week, which enables people who are Deaf or have a hearing and/or speech impairment to have access to the telephone comparable to the standard telephone system for all Australians (ACMA, 2010b, p. 1). The legislative obligations are outlined under Part 3 of the Telecommunications (Consumer Protection and Service Standards) Act (1999). The NRS is funded through a levy imposed on telecommunications carriers with a gross (telecommunications) revenue of $10 million or more (ACMA, 2010a). This is collected by ACMA on behalf of the Federal Government and then passed on to the provider (2010a). Since 1st July 2006, Australian Communication Exchange Ltd has been responsible for the service delivery, and WestWood Spice Pty Ltd has provided the outreach component, which consists of promotion for the service and help desk facilities (ACMA, 2010b). The annual NRS Users Satisfaction Survey, which was last conducted in March 2011, revealed the service overall received a satisfaction level of 92 percent and a dissatisfaction level of just 3 percent (ACE, 2011). These user satisfaction levels are not categorised according to type of relay service, and ACMA (2011) reports that only 2.7 percent of the total outbound calls[2] were SSR for the year 2009–10, so it is not possible to obtain user satisfaction levels for SSR specifically.

The NRS works by providing a relayed call between two parties, one or both of whom may have a communication impairment. A Relay Officer facilitates communication between the other two parties. Depending on the type of service, the facilitation can involve converting voice communication to text or vice versa, or re-voicing (ACMA, 2010b). In 2000, the NRS

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[2] A call placed by a Relay Officer on behalf of a caller is referred as an outbound call.

service expanded to include the Speech-to-Speech Relay[3] (SSR) component to serve the speech impaired community (Power & Power, 2004; Power, Power, & Horstmanshof, 2007). In "History of Speech-to-Speech", Dr Bob Segalman (2006), an academic who uses AAC, recounts the genesis of the idea of SSR and the commencement of the first SSR service in 1996 in California. He further describes the national adoption across the United States of America in 2000, the same year it was introduced in Australia.

As a result of the recent NRS Review, the Australian Communications Consumer Action Network (ACCAN) (2011) put forward recommendations to improve SSR suggesting "Consideration should be given to accrediting Speak and Listen Relay Officers as 'speech interpreters'" (p. 23). This would enhance the role of the SSR Relay Officers by broadening their role to include interpretation as well as revoicing. This would be similar to the service provided in Sweden by the Swedish Postal and Telecom (2011) service called Teletal, which involves an enhanced relay service delivered to people with speech impairments in Sweden. The difference between this service and SSR is that Teletal provides additional services such as memory support, note taking during the call and offers interpretation as opposed to re-voicing.

To understand the relay service from a Bourdieuian perspective is to see the service as a communication strategy people with CCN can choose to employ to communicate in their social fields. The service is one of many ways people with CCN can compete more fairly for social capital using telecommunications. One such example is the use of the relay service to overcome the experience by people with CCN of being devalued due to their inability to articulate in a socially acceptable manner, as highlighted by Edwards and Imrie (2003). In such a case, where the habitus of the communication partner devalues the caller's abilities,

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[3] The service is known internationally as Speech-to-Speech Relay however the Australian Government renamed each type of relay service provided in Australia. Speech-to-Speech relay was renamed to Speak and Listen. The international term is used in this thesis.

they could either dominate the conversation or not engage fully in the conversation. In using the relay service, the Relay Officer intercedes by communicating with the partner in an attempt to provide a degree of equality in the call, thus providing control to the caller with CCN.

The caller with CCN and the Relay Officer would have a habitus associated with the field of the relay service, based on their dispositions and past experiences. In other words, they both know how the call works and how to conduct such a call. On the other hand, someone without experience of the relay service receiving a call for the first time is required to learn the habitus. It can be a foreign experience receiving a relayed call for the first time. The skills and experience required to use the relay service would be considered cultural capital, whereas the relationships enhanced by the communication are social capital.

2.7 Emergency Call service

Australia has a nation-wide emergency call service to assist people who are in emergency crisis, such as life-threatening or time-critical events. There are three primary emergency numbers. Two of these are operated through Telstra, the Triple-Zero (000) used by fixed-line and mobile phones, and 112 accessible on the GSM network. The text-based (106) emergency phone number is operated through the NRS (ACMA, 2010a). However, ACCAN (2011) suggests SSR " ... has proven to be unreliable, and there are particular concerns regarding making 000 calls, because in times of stress, a user's speech may become less easily understood" (p. 19). This highlights the inequalities faced by people with CCN in emergencies and in society in general.

An SMS emergency service made available to people who are Deaf[4], or who have a hearing or speech impairment, has been trialled in the United Kingdom since 2009 (emergencySMS,

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[4] The usual convention of using "Capital D: Deaf" when referring to members of the signing Deaf community have been adopted.

2009). ACMA and the Department of Broadband, Communications and the Digital Economy (DBCDE) have investigated issues surrounding introducing such a service in Australia (ACMA, 2010a). The Minister for DBCDE announced on 20 April 2010 the government will be introducing SMS access to the emergency services for people who are deaf and hearing/speech impaired (Conroy, 2010).

In addition, the Australian Communication Exchange (2011) has announced that a newly developed emergency call service smart phone application, called the Emergency Internet Protocol Relay (EIPR), will soon be available to trial. The application has been designed to enable users who are Deaf, or have a hearing or speech impairment, to make calls to emergency services through the NRS efficiently and potentially faster than a standard Triple-Zero emergency phone call.

2.8   Video-Assisted Speech-to-Speech Relay

Video-Assisted Speech-to-Speech Relay (VAS) assists people with CCN to make telephone calls. The service is a modernisation of SSR, a convergence of traditional SSR and Video Relay Service (COAT, 2011). Video Relay Service is enabling people who are Deaf to make telephone calls via relay service utilising sign language (Brunson, 2009). A VAS call is similar to a traditional SSR, yet Voice over Internet Protocol (VoIP) technology is used for the communication between the person with CCN and the Relay Officer[5] (Simpson, 2011).

Generally, people with CCN use multiple modes of communication simultaneously during conversation, including " ... speech, gestures, manual signs, facial expressions, electronic and nonelectronic [sic] technologies" (Blackstone, et al., 2007, p. 192). Alant et al. (2006) elaborate on this explaining face-to-face communication is naturally multimodal, people communicate using a variety of modes, speech and non-speech, to relay a message. They highlight these communication modes can be strongly affected by context and can be

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[5] In the US, Relay Officers are known as Communication Assistants (CA) or Operators.

extremely elaborate and have the potential to enhance the message. Therefore, Relay Officers in VAS calls are able to enhance communication not just by listening to the caller's voice or AAC device, but also by making use of visual cues (Simpson, 2011). The use of this technology therefore enables the person with CCN to employ multiple modes of communication during telephone calls.

VAS services are in various stages of implementation in the USA, Finland, New Zealand and Australia. The United States FCC National Broadband Plan recommends improved accessibility to online technologies and specifically recommends investigating the potential benefits of a VAS service (Federal Communication Commission, 2010). The Honkalampi Foundation has already introduced a VAS successfully in Finland. This implementation of VAS provides users with the option to use video alone or a combination of video and onscreen symbol based communication (M. Heiskala, personal communications, 4 October, 2010). VAS was introduced in New Zealand in October 2011 (P. Buckrell, personal communications, August 18, 2011).

In addition to enhancing communication for people with CCN making and receiving telephone calls, the modernisation of traditional SSR would result in other benefits. Firstly, VAS would increase the choices of communication strategy available to people with CCN to use in their employment (Simpson, 2011). Secondly, with the close relationship between manufacturers and users of AAC devices, Simpson (2011) suggests an introduction of VAS could have other benefits to users as it could drive manufacturers to include Internet capabilities to devices. However, the author argues the potential users of VAS would not all be users of AAC, therefore the development of VAS should not be solely for AAC devices, but also include mainstream devices such as mobile phones.

Although not explored by this thesis, Buckrell (personal communications, August 18, 2011) makes an interesting point that in New Zealand it was proposed by the service provider to

consult users as to whether or not the image of the "relay assistant" should be blocked in calls. This raises the issue of the usefulness of the caller with CCN being able to see the visual cues of the Relay Officer, in other words, whether communication can be enhanced by the use of visual cues by both communication parties. However, blocking the Relay Officer's image would be contrary to the position advocated by Blackstone et al. (2007) who argue that visual cues are significant to both communication parties in constructing meaning.

Collier et al. (2010) suggest although AAC devices can assist in certain situations, many people who use AAC find they also rely on having someone else to assist them to communicate, especially with unfamiliar people. In their research, they found trained communication assistants can assist people with CCN to participate in their communities. However, they remark that there is little literature on the type of obstacles that can be overcome with the help of a communication assistant. Therefore, their research also provides insight into the usefulness of Relay Officers, as they provide similar services to a communication assistant, except the service provided by the Relay Officer is remote.

2.9   Conclusion

In the 21st century telecommunications has become an important method of accumulating social and cultural capital in western society. The literature discusses the types of barriers inhibiting people with CCN from full participation in society, including barriers to telecommunications. Research has also highlighted the need for increased support for people with CCN to improve and maintain their social capital through building their social networks. There have been calls for SSR to be modernised for people with communication disabilities, by introducing Video Assisted Speech-to-Speech Relay, yet there is no in-depth empirical research relating to the usefulness of the service.

In addition, there is very little literature on what kinds of telecommunications are actually used by people with CCN. It is valuable to use a postmodern approach to gain an

understanding of the situation through the experience of people with CCN who are participating in society through telecommunications. In turn, by understanding their struggle in their social fields, research can start to answer what support can be provided to help them in this struggle to maintain and accumulate power and control in their own lives.

In reviewing the literature, there have been Speech-to-Speech Relay services operating in numerous countries for the past decade. Surprisingly, given this period of operation, there appears to be no systemic evaluation of the usefulness of SSR for people with CCN. Despite the fact the Australian government requires that the NRS surveys its users annually on their overall satisfaction with the service (ACMA, 2010a), data is not collected on the perceived usefulness of the service and is not broken down to individual relay service types.

Based on the gaps in the existing literature, this research investigates the perspectives of people with CCN on the usefulness of their current methods of accessing telecommunications and on the usefulness of VAS. Both perspectives are compared in an attempt to understand the barriers people with CCN face in accessing telecommunications to accumulate social capital.

3 Methodology

3.1 Introduction

This research project explored the current methods that people with CCN utilise to access telecommunications and their perspective of the usefulness of Video-Assisted Speech-to-Speech Relay (VAS). All of the participants in this research project have both physical disabilities and communication difficulties. The researcher also has a physical disability and Complex Communication Needs (CCN). Therefore, the project design took into account the ability of both the participants and the researcher. The research tools used were online surveys and an online focus group. Human Research Ethics approval was obtained from the University of South Australia's Human Research Ethics Committee prior to the commencement of the research.

3.1.1 Research Questions

- What are the perspectives of people with CCN on the usefulness of their current methods of accessing telecommunications?
- What are the perspectives of people with CCN on the usefulness of a VAS?
- How do the perspectives of people with CCN on the usefulness of their current methods of accessing telecommunications compare to their perspectives on the usefulness of a VAS?

3.2 Methodological issues

The understanding of disability has evolved over many decades; however, it changed dramatically from the 1960s to 1970s when the focus shifted away from the medical model to place greater importance on how society disables people, rather than on the impairment itself (Mercer, 2002).

During the early 1990s a new approach to disability research emerged. Oliver used the word "emancipatory" to describe this at-the-time radical approach to disability research. The

emancipatory research paradigm was a response to criticism of existing disability research from both people with disability and researchers (with and without disability) (Zarb, 1992).

There have been debates in the disability studies literature for the past two decades centred on disability research ideology, ethics and methodology. Kitchin (2002) notes the debate has been mostly one-sided and led by British sociologists who argue that there needed to be a shift from disability research predominantly undertaken by researchers who have no personal experience of disability. These sociologists argue that this approach has inherent problems because the focus is on research benefitting researchers, rather than the researched. They argue that researchers without a disability are not always the best people to interpret the data; only people with disabilities " ... can truly interpret and present data from other disabled people" (Kitchin, 2002, p. 2). For instance, in the past, research has often focused on the efficacy of a particular intervention and has failed to take into account the knowledge and experiences of the people being researched (Kitchin, 2002).

The debate centres on whether non-disabled researchers can legitimately research disability and manage to demolish the unequal power relations highlighted by the social model. In this vein, disability scholars have argued that research must always address the power imbalance and oppressive situations faced by people with disabilities (Barnes, 1992; Stone & Priestley, 1996; Zarb, 1992). The literature suggests an emancipatory research model, which is about describing the oppression elements surrounding the experience and narratives of people with disabilities, is appropriate as it improves the understanding of disability within the social model (Barnes, 2003).

Kitchin argues that all research in this field must be "both emancipatory (seeking 'positive' societal change) and empowering (seeking 'positive' individual change through participation)" (Kitchin, 2002, p. 2). However, some scholars are critical of the way that the emancipatory research framework is being prescribed as the only acceptable way of doing

disability research (Danieli & Woodham, 2005; Mercieca & Mercieca, 2010; Walmsley, 2001). In particular Mercieca and Mercieca (2010) argue that this framework gives researchers a false sense of security that their research will not be oppressive if they adhere to all the principles. This current research recognises that the principles in themselves do not prevent a project from being oppressive and the researcher has thus endeavoured to respect the participants as peers.

Danieli and Woodham (2005) warn that there is a risk that only the voices that align with the researcher's political persuasion will be heard in an emancipatory research framework. This is a legitimate concern and therefore this research project has been consciously designed to listen to those who have "little or no speech".

While this research is designed, conducted and the data interpreted by the researcher, both the researcher and the people being researched have disabilities. The researcher is a member of the community being researched, which may enrich the understanding of the data. A focus group was conducted after the survey phase, which provided the researcher with an opportunity to seek feedback from the participants and enabled them to " ... check facts, offer alternative explanations or verify researcher interpretations" (Kitchin, 2002, p. 4).

This research was developed in keeping with the emancipatory framework. It is hoped that people with disabilities and their organisations will use the research to contribute to the growing body of evidence aimed at facilitating a process, leading to the removal of barriers to participation in telecommunications.

3.2.1 Current Project

Nocera, Dunckley, and Sharp (2007) discuss the notion of usefulness of software applications and recognise that developers and users often have widely different perspectives. This concept could be extended to the field of telecommunication services for people with CCN. Users may have widely different perspectives about the usefulness of these services than professionals,

service providers and policy makers. This research is based on " ... the assumption that usefulness is not inherent in a [service] but is socially constructed in situ, once users begin to interact with it" (Nocera, et al., 2007, p. 153). Understanding users' perspectives is vital when developing services in this field. If people do not believe a service is useful, they will not use it, no matter how effective the professionals perceive it to be. However, because people with CCN have speech, voice and/or language impairments, their voices often remain unheard.

The literature recognises individuals with CCN, their supporters and their families, face many struggles and find themselves problem solving on a day-to-day basis. Hence, as they are knowledgeable in the field, it is good practice to involve them throughout the research process. Alm and McGregor (2006) suggest this educates other members of research and development teams about issues surrounding individuals with CCN, as well as improving project outcomes. Björck-Åkesson, Granlund, Light and McNaughton (2000) argue individuals with CCN and their families must be involved in the defining of the problem and finding solutions. The research into an interface system linking mobile phones via an interface speech generating devices by Nguyen et al. (2008) confirms positive outcomes are achieved by having users contributing into the developmental process. Therefore, this research focuses on the perceptions of people who use AAC and telecommunication.

The aim of the focus group was to give the participants an opportunity to co-construct a collective perception of their current methods they employ to access telecommunications and their perspective of the usefulness of VAS. The process enabled the researcher to gain an insight into the participants' Technological Frame (Nocera, et al., 2007) to understand their current methods of accessing telecommunications and perspectives on the usefulness of different methods, in order to answer the research questions.

3.2.2 Recruitment Issues

The original proposed research design was modified to address the difficulties experienced in recruiting participants to the study. Despite these modifications, the recruiting difficulties remained. The researcher contacted Jan Ashford, Chief Executive Officer of one of the major advocate agencies for people with CCN in Victoria, Australia, to discuss the recruitment issues preventing the project from progressing. The three main issues Ashford (Personal Communications, January 19, 2011) highlighted were the need for personal contact with potential participants, distributing information through support workers and the low usage of telecommunication by people with CCN. She expressed the need for what she called "bridge building" to this particular cohort of people with CCN by highlighting the importance of personal contact with the potential participants. People with CCN are less likely to respond to unfamiliar people than people without CCN. Ashford goes on to explain from their experience to disseminate information the agency finds "[s]taff or workers become unofficial gate-keepers." These are, in most cases, the key people within the life of the person with CCN and for successful participation these people need to be consulted with first. Lastly, she suggests many people with CCN are not frequent users of telecommunications. Although Barnes (2003) notes people with disabilities are suspicious of non-disabled researchers, this researcher questions whether the low number of respondents was due to potential participants being more suspicious of a researcher with a disability.

Ideally, research participants should be independent of the social networks of the researcher. However, as Ashford (Personal Communications, January 19, 2011) points out, research recruitment in this cohort is heavily dependent on the utilisation of the researcher's social network. The majority of the participants had a relationship with the researcher directly or indirectly through a person who knew the researcher. The participants from the United States and Ireland were a direct result of the researcher attending an international conference prior to the recruitment.

3.2.3   Methodological issues considered

In designing this research, the researcher also had to devise strategies for dealing with the challenge of both researcher and participants having physical disabilities and communication difficulties. Many things that are taken for granted in research needed to be reconsidered, these include:

- time and energy required by participants to fill in surveys and participate in the focus group

- literacy issues amongst the cohort

- time and energy required by the researcher to coordinate tasks, analyse surveys and participate in the focus group

- potential influence from the participants' personal assistants or family members when assisting with typing responses.

As a result, it is hoped some of the issues raised in this project will contribute to methodological debates surrounding disability research and research by people with disabilities.

3.3   Phases of project

There were four phases in the project:

1. Recruitment Phase
2. Survey Phase
3. Focus Group Phase
4. Analysis Phase

3.3.1   Recruitment Phase

A recruitment email (see Appendix A) was distributed to professionals working in the disability field, interested persons known to the researcher and two electronic mailing lists (Australian Group on Severe Communication Impairment (AGOSCI) and Severe Communication Impairment Telecommunications). The email provided the details of the project, the criteria for participation and a web link to the online anonymous survey. The

introduction to the survey had a web link to the Participant Information Sheet providing the participation information for the research project with the contact details of the researcher and supervisors, including the Executive Officer of the UniSA Human Research Ethics Committee. The first question asked respondents to confirm their eligibility.

The inclusion criteria for respondents were:

(a) the participant needed to be over the age of 18 years at the time of the survey

(b) the participant must be a user of an AAC device

(c) the participant needed to have a level of literacy adequate to complete the survey and participate in the online focus group.

The inclusion criteria did not specify that participants must identify as having a physical disability. The recruitment email and Participant Information Sheet did state, however, that the participants would be people with CCN. However, all participants identified as having a physical disability.

At the end of the survey, participants were given the details of the focus group phase and presented with an option to indicate their willingness to participate. Each survey response was reviewed individually to determine whether the respondent indicated that they met the criteria and the extent of completeness of the survey.

After the surveys were reviewed, a three-week online focus group was conducted to further explore issues arising from the survey. In cases where the survey responses indicated that the respondent may not meet the criteria and they expressed interest in participating in the forum, the researcher engaged in email correspondence to determine their eligibility.

3.3.2   Survey Phase

Research suggests online tools such as internet surveys and focus groups are efficient methods of collecting data from this population of people who use AAC (Bryen, 2008; Dattilo, Estrella, Estrella, Light, McNaughton and Seabury, 2008; McNaughton & Bryen,

2007). Some of the benefits include cost, time and physical energy savings for both participants and the researcher since respondents are able to respond in their own environment and at their own pace (McNaughton, Light, & Groszyk, 2001). The research tool used to collect data in this phase was an anonymous online survey.

Taking into account the physical limitations of the participants and to ensure the data collection process did not become too demanding, the number of questions included in the survey was limited to twenty-four and the majority of these questions were in multiple-choice format. There were some open-ended questions included to give the participants the opportunity to contribute additional information and to elaborate on any issues not considered in the construction of the survey instrument.

The questions included demographic information, such as age, gender and type of disability, the AAC device(s) used, communication modes and information about the participant's current use of technology and telecommunications. Most of the questions relating to technology and telecommunications employed Likert scales and multi-select lists. There were two questions assessing the confidence of the participants in making different types of phone calls. One question assessed the participant's perception of the usefulness of a VAS in making the same types of phone calls. These three questions all used the same set of call types such as calling family, ordering a pizza and booking a taxi. A copy of the survey is in Appendix B.

Respondents were invited to view a ten-minute online video[6] introducing the concept of VAS and how to use it as preparation for their participation in the survey. The video introduction highlighted a number of techniques for using a VAS system. The video was uploaded to YouTube and only accessible by using a particular URL, which was embedded in the survey. The respondents were able to view the video by selecting the embedded hyperlink.

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[6] Directed by the researcher and produced by a media student.
The video can be view at http://youtu.be/arlOhxjBaNE

The survey provided a list of 11 types of calls presented in three separate questions using Likert scales. The first two questions asked respondents to rate their confidence using different methods to make these types of calls on a five-point scale (Wouldn't attempt, Not Confident, Somewhat Confident, Confident, Very Confident). The third question related to a hypothetical method of making these same types of calls on a four-point scale (Not at all useful, Somewhat useful, Useful and Very Useful). Rather than ask the respondents to rate their confidence using this hypothetical method, they were asked to rate its perceived usefulness since it was determined that confidence would be difficult to measure in a hypothetical situation. In comparing the responses to these three questions, 'confidence' and 'perceived usefulness' were considered to be equivalent. It is acknowledged the difference between the four- and five-point Likert scales is a weakness in the research method.

3.3.3　Focus Group Phase

Dattilo, et al. (2008) argue that online focus groups are an effective method for conducting research with people with CCN. The researchers discussed some advantages and disadvantages before highlighting examples of how research has been successfully conducted using online focus groups. The main advantages include access to more participants and participants have 24-hour access to the focus group in their own environment. They suggest further research shows the participants can interact more openly with a moderator who uses AAC and has had "similar life experiences" (Dattilo, et al., 2008).

Respondents to the survey were also invited to participate in a three-week online focus group. They were advised that their participation would involve a time commitment of up to one hour each week. The purpose of the online focus group was to gain richer qualitative data to help understand and interpret the survey data. The survey data were analysed to identify gaps and develop questions for the online focus group.

The online focus group was hosted on the researcher's personal website at *forums.thedazz.com* for three weeks following completion of the Survey Phase. The methodology for the online focus group was modelled on Dattilo et al. (2008) and was conducted using the latest version of the Phorum[7] web-based software, a password-protected internet bulletin board tool, which allows text-based discussions between groups of individuals. The forum was only accessible to the research participants and was moderated and the discussion facilitated by the researcher. The researcher's supervisors also had access to the site and data.

Recognising the participants would have varying literacy and physical abilities, and that typing can be difficult and tiring, participants were encouraged to use strategies ranging from brief text statements and dot points to more detailed responses. As the moderator, the researcher asked follow up questions if more information was required.

Participants who indicated an interest in the online focus group received a follow-up email. Two of the participants were identified as not meeting the criteria. After confidential email follow up, the researcher was informed one did not have the literacy level required and the other did not use an AAC device. These two were not included in the survey data or the focus group.

The information email provided an introduction to the online focus group, login details and information about posting messages. Participants were encouraged to visit the website a few times each week, contribute to each discussion topic posted and participate in a respectful manner.

Each week during the Focus Group Phase of the project, the researcher created a new discussion thread with a question for discussion. The type and wording of these questions was

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[7] Phorum Open Source PHP Forum Software: www.phorum.org

shaped by the survey responses and participant comments in the forum so as to facilitate conversation on these topics. Topics discussed in the focus group included preferred telecommunications method, personal experiences of successful communication and whether access to telecommunications empowers people.

In the last week of the Focus Group Phase, an email was sent to all the participants reminding them the forum would close at the end of that week and encouraging them to take the opportunity to express their opinions on each of the discussion threads.

3.3.4   Analysis Phase

Due to the small sample size of 13 respondents, it was only possible to analyse the survey data using descriptive statistics. Therefore, the data is summarised and described by the use of means, standard deviations and medians. Contingency tables were used to identify relationships between the type of telecommunications access methods, technology use and type of calls. The focus group data were analysed to identify any common themes emerging from the data. The results from this analysis and a discussion of the implications of the findings are presented in the next two chapters.

4 Results

4.1 Introduction

The following sections present a summary of the findings of the online survey and focus group. This chapter commences with an overview of the survey responses, such as the number of surveys received, reasons for excluding surveys and the number of useable surveys. The first section presents demographic information about the survey respondents and the online focus group participants. The following sections report the findings from a descriptive analysis of survey responses. Medians of the data are presented rather than means, since the data is generally skewed. Detailed discussion and interpretation of the results are discussed in Chapter Five.

4.2 Survey Responses

The findings reported in this chapter are presented using only descriptive summary data. It was not possible to conduct inferential statistical analysis due to the low number of respondents and the design of the survey.

A total of 24 surveys were received and out of these:

- three participants indicated that they did not meet the criteria

- five of the surveys were incomplete because although the respondents indicated that they met the criteria, they either did not answer any of the following questions, did not specify which AAC device they used, or their answers were contradictory

- one respondent indicated that they met the criteria and expressed an interest in participating in the focus group, but it was apparent from email correspondence that this respondent did not meet the independent communication criteria, therefore their survey are excluded from analysis

- one respondent indicated that they met the criteria and expressed an interest in participating in the focus group, but on examination of survey responses and through email correspondence, it was revealed that they did not meet the criteria for using an AAC device, therefore their survey has also been excluded
- one survey was not sufficiently complete to be useful because the respondent exited the survey before reaching the question about the type of telecommunications used.

Therefore, 13 surveys were deemed useable, however, not all of respondents responded to each of the survey questions. Six survey respondents indicated their interest in participating in the online focus group.

4.3   Demographic Analysis

In this section, the demographic details of the 13 survey respondents are presented, followed by information more specifically relating to the six respondents who participated in the focus group.

4.3.1   Survey Respondents

Table 1 presents basic demographic information relating to the 13 respondents to the survey. A majority of the respondents (7, 53.8%) are international (Ireland, the United Kingdom and the United States). The gender distribution is 7 (53.8%) male and 6 (46.2%) female. All participants have post-secondary education, with over half (7, 53.8%) having university qualifications.

Table 1: Demographic Information[8]

Demographic information	Male	Female	Education	n
Age	n	n	High school	0
18 - 24 years	0	0	Diploma (e.g. TAFE or 2 year college)	6
25 - 34 years	1	1	Tertiary degree	4
35 - 44 years	3	2	Post graduate studies (i.e. Masters or PhD)	3
45 - 54 years	3	0		
55 + years	0	3		
Total	7	6		

Country	n	Disability	n
Australia	6	Cerebral Palsy	11
Ireland	1	Dystonia	1
United Kingdom	1	Traumatic Brain Injury	1
United States	5		

Table 2 summarises the AAC devices and access methods the respondents indicated that they use. These AAC devices and access methods are classified into three categories of device and three categories of access. The majority of respondents use a dedicated AAC device, such as a Dynavox or a Pathfinder, and two respondents use more than one AAC strategy. Approximately two thirds of respondents reported that they prefer to use a direct selection[9] method to access their AAC device. The response "Mobile phone" to the question regarding the type of methods respondents use to access their AAC device was interpreted as direct selection, as it was presumed the respondent uses their mobile phone as an AAC device by directly using the keypad to type messages for communication partners to read.

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[8] Due to the low numbers, the demographic information is reported in a way that avoids easy identification of individual respondents.

[9] Direct selection means the user types by physically using the keys on the device as opposed to using alternative input devices such as switches for scanning

Table 2: AAC Devices Used/Access Method

	n	Scanning by chin switch	Head pointer	Direct Selection	No Answer
Dedicated-AAC device (i.e. Dynavox, Pathfinder)	8	1	2	5	
AAC Software (i.e. EZ-Keys)	2			2	
Mainstream (i.e. Mobile phones and tablets)	3			1	2

The respondents are all users of AAC devices, though not all participants use their devices as their primary communication method. The two most used primary communication methods are natural speech (9, 69.2%) and an AAC device (7, 53.8%), closely followed by the use of gestures/body language (5, 38.5%) and sign language/finger spelling (2, 15.4%). Four participants reported they use natural speech alone. Nearly half the respondents indicated using multiple primary communication methods, with four using both natural speech and an AAC device, and three using natural speech, gestures/body language and an AAC device. From the responses to the open-ended *Other* option, two use writing text in face-to-face communication (e.g. notes on paper, using the text facility on a mobile phone).

Participants were asked to rate six statements[10] relating to their level of confidence using technology. The six responses are converted to an index score to give an overall indication of the user's confidence using technology. The calculation of the index is the average of the scores. The second and fourth statements indicate a lack of confidence rather than a presence of confidence, so these responses are reversed before averaging. The index for all respondents ranged from low to middle, suggesting a low to medium confidence in the use of technology with a mean of 2.2 out of 5.

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[10] The rating scale used for the six statements was 1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree nor Disagree, 4 = Agree, 5 = Strongly Agree.

4.3.2 Focus Group Participants

As a part of the survey, respondents were invited to participate in a three-week online focus group. At the completion of the survey period, the six survey respondents who expressed interest in participating in the focus group were sent an introductory email. Over the period of the focus group, five questions were posted (listed in Appendix C). Unfortunately, of the six participants, two of the group did not respond to any of the questions. One participant posted one response to one question, leaving only three active members plus the researcher as moderator.

Table 3 presents basic demographic information relating to the six focus group participants. Of the active members, there are one male and two females. One is from the United States and two from Australia. Two indicated they use natural speech as their main mode of communication, one uses gestures and body language.

Table 3: Demographic information of the Focus Group Participants

Gender	*n*	Disability	*n*
Female	4	Cerebral Palsy	5
Male	2	Dystonia	1
Age	***n***	**Preferred Access Methods**	***n***
18 - 24 years	0	Direct Access	5
25 - 34 years	1	Scanning	1
35 - 44 years	3		
45 - 54 years	1		
55 + years	1		
Country	***n***	**Education**	***n***
Australia	2	High school	0
Ireland	1	Diploma (e.g. TAFE or 2 year college)	3
United Kingdom	0	Tertiary degree	1
United States	3	Post graduate studies (e.g. Masters or PhD)	2

4.4   Current Telecommunications Access Methods

This section addresses the first research question by presenting the data relating to the respondents' current methods of accessing telecommunications. The data presented include the type of telecommunications used by respondents, the telecommunications ac?cess methods used for various interaction types, the types of relay services the respondents employ

and the respondents expressed confidence in using their current access methods for various interaction types.

4.4.1 Type of Telecommunications Used

Respondents reported using various types of telecommunications and this is summarised in Table 4. Seven respondents do not use mobile phones for speech calls, but four respondents use this method independently. Nine respondents use Short Message Service (SMS) independently and of the three who did not use SMS, the raw data shows that two do not use mobile speech calls. Two respondents do not use VoIP at all, nine use VOIP independently and one uses VoIP with assistance.

Table 4 Type of telecommunications used

Answer Options	*n*	Independently use	Use with assistance	Don't use
Landline Telephone	13	6	4	3
Email	13	13	0	0
Mobile/cellular phone (Speech)	13	4	2	7
Mobile/cellular phone (SMS)	12	9	0	3
VOIP (eg Skype)	12	9	1	2
Text chat	13	9	0	4
Video call	12	6	2	4
Social Networking, eg Facebook	13	13	0	0

Several participants indicated they have multiple methods of accessing telecommunications. The following response highlights the way users choose different methods for different reasons:

> "I am generally a text/email user on a daily basis but there are days when i [sic] need to use the NRS and i [sic] use TTY because it is 'quick' and reliable but it is impersonal..."

A common theme is the use of text-based telecommunications (e.g. SMS, email, instant messaging and social networking sites). All respondents use email and social networking sites independently. Although the respondents generally expressed a low to medium level of technology confidence, all are users of internet-based telecommunications methods. The

following comment by one of the focus group participants highlights this theme and gives possible reasons.

> "My favorite [sic] telecommunication method so far is email or text because they are so universal, everyone uses them now to communicate so I find it makes things simpler. I do use a TTY when I have to, but find it not as user friendly. Sometimes use Facebook [sic]."

Table 5 shows a summary of the telecommunication methods used by respondents for different interaction types. The most common interaction type is *Talking with friends*. The three main findings relate to the use of email, making emergency calls by landline and making video calls. First, email is the most commonly used method in general across the interaction types, with scores of 10 (76.9%) in *Making a complaint*, 10 (76.9%) in *Doing business* and, highest of all, 11 (84.6%) in *Talking to friends*. Landline is the second most common telecommunications method used. Nine respondents indicated they would use a landline to make emergency calls but only six indicated that they would be able to call independently. Interestingly, one respondent indicated they would make an emergency call using social networking tools. Finally, six respondents indicated they use video calling independently. However, only three respondents indicated they would actually make video calls for at least one of the listed interaction types. This low result might be due to the low usage of video calls generally.

The following comments made by respondents underline several barriers they face in accessing telecommunications.

> "When I have to, say, order a taxi, I use a landline but I get my personal assistant to relay the necessary information."

> "I fax info to my GP or use TTY IP Relay. The taxi LAN line won't accept TTY calls. And finally, my family got a low score because my mom won't accept anything but traditional phone calls."

> "If I'm out I can't text 000 on my mobile."

All respondents indicated using multiple telecommunications access methods. All use email and social networking sites. Most use mobile phones, mainly for SMS communication rather than speech calls. Thus, respondents predominantly use text-based telecommunications and landline telephones.

Table 5 Telecommunication method versus interaction types

Answer Options	n	Land line	Email	Mobile calls	SMS	VOIP	Text chat	Video call	Social Network
Talking with close family members	12	6	8	4	7	6	4	2	6
Talking with friends	13	5	11	3	9	7	6	2	9
Ordering home delivery such as pizza	11	8	4	1	0	0	0	0	0
Booking a taxi	10	6	3	1	3	0	0	0	0
Speaking with your doctor (GP)	10	7	6	0	0	0	0	0	0
Contacting a call centre with important information	10	6	6	0	0	0	1	0	0
Making a complaint	11	3	10	0	2	0	1	0	1
Doing business	11	4	10	0	3	4	2	1	2
Making a 000 emergency call	10	9	1	1	1	0	0	0	1

4.4.2   Relay Services

This section presents the findings on the types of relay service used by respondents, years of experience and frequency of use.

Out of the seven respondents who identify as users of SSR, only four use SSR on a regular basis. Four SSR users have between five and ten years' experience and three have five or less years' experience. All of the users of SSR are 35 years or over, and a gender mix of five females and two males. The SSR users reside in the United States (4, 57.1%) and Australia (3, 42.1%). The majority of these users use the service only 1-6 times a year, one uses it monthly

and only one uses it daily. Five respondents use more than one type of relay service, whereas three use only one type of relay service.

The comment below highlights the perceived impersonal nature of using a telephone typewriter (TTY) based relay service, such as *Type and Read*, because of the third person involved in the call (i.e. the Relay Officer).

> "I am generally a text/email user on a daily basis but there are days when i [sic] need to use the NRS and i [sic] use TTY because it is 'quick' and reliable but it is impersonal..."

When asked to reflect on a time when they realised that using telecommunication was useful in helping them to be a part of their community, two Focus Group members wrote the following:

> "In 1996, during the second STS[11] trial in California, I was on the phone using STS 8 hours a day recruiting new users. I can remember that my assistant and I were both on the phone all the time. We called anybody we could think of that might know a potential STS user. […] The independence was wonderful. I want everybody who can use STS to know about it."

> "It made me independent on the telephone and allowed me to do many things that I could not do myself before on the telephone"

4.4.3   Confidence in using in telecommunications access methods

The survey investigated the confidence of respondents in conducting various types of interactions using their current telecommunications methods and using SSR. The data is summarised in Table 6. The table lists the interaction types along with participants' reported levels of confidence in using their current methods and SSR. All respondents reported their confidence in using their current access methods and 12 respondents reported their perceived confidence in using SSR. As only seven respondents identify as users of SSR, the description of data in Table 6 is broken down further to include comparisons between respondents with SSR experience (SSR Users) and respondents without SSR experience (non-SSR Users).

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[11] The acronym use for Speech-to-Speech Relay is STS in the USA.

While respondents who use SSR might have included their use of SSR in their current methods response as well, it appears this was not generally the case.[12]

Generally, respondents expressed greater confidence in using their current telecommunications access methods than using SSR for most of the interaction types.

Table 6: Confidence in using current access methods and SSR

Interaction type	Current Methods			Using SSR		
	n	$\tilde{x}$	*sd*	*n*	$\tilde{x}$	*sd*
Talking with close family members	13	4.0	1.50	12	2.00	1.85
Talking with friends	13	5.0	0.77	12	1.00	2.00
Ordering home delivery such as pizza	13	2.0	1.42	12	1.50	1.60
Booking a taxi	13	2.0	1.46	12	2.50	1.75
Speaking with your doctor (GP)	13	3.0	1.55	12	1.00	1.56
Contacting a call centre with important information	12	2.5	1.38	12	2.50	1.98
Making a complaint	13	3.0	1.83	12	2.00	1.59
Doing business	13	3.0	1.57	12	2.00	1.80
Making a 000 emergency call	13	3.0	1.39	9	3.00	1.27

n = Number of Responses; *sd* = Standard Deviation; $\tilde{x}$ = Median;

Scale: 0 = N/A, 1 = Wouldn't Attempt, 2 = Not Confident, 3 = Somewhat Confident,
4 = Confident, 5 = Very Confident

As per Table 6, respondents expressed greatest confidence in using their current methods for *Talking with friends*, with a median of 5.0 (Very Confident), and *Talking to close family members*, with a median of 4.0 (Confident). The respondents expressed the least confidence in using their current methods for *Ordering home delivery* and *Booking a taxi* with medians of 2.0 (Not Confident). However, further analysis reveals the seven SSR users expressed more confidence in *Ordering home delivery*, with a median of 3.0 (Somewhat Confident).

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[12] This conclusion was reached by comparing the median response for the different communication types for SSR users with current methods versus using SSR.

The highest expressed confidence using SSR, is in *Making a 000 emergency call* with a median of 3.0 (Somewhat Confident) and the lowest are *Talking to friends* and *Speaking with their doctor*, both with a median of 1.0 (Wouldn't Attempt). However, further analysis of the raw data reveals an unexpected difference between SSR users and non-SSR users, which is not apparent in Table 6. The least expressed confidence for non-SSR users is for *Ordering home delivery*, median of 0.0 (N/A). SSR users expressed least confidence in *Speaking with their doctor*, with a median of 1.5 (between Wouldn't Attempt and Not Confident) and expressed the most confidence in *Talking to friends*, *Contacting a call centre* and *Making a 000 emergency call*, all having a median of 4.0 (Confident).

An SSR user, with 3–5 years experience, indicated she is Not Confident using SSR for *Talking to close family members* yet commented, "my family got a low score because my mom won't accept anything but traditional phone". It is worth noting five non-SSR users are Very Confident in using their current access methods to *Talking with close family member* and the SSR users are slightly less confident with four users Confident and one user Very Confident.

Out of the nine interaction types, seven have medians of 0.5 (between N/A and Wouldn't Attempt) as three non-SSR users selected the N/A option. For the *Ordering home delivery* interaction type, with a median of 0.0 (N/A), four non-SSR users expressed the N/A option.

The overall level of confidence median for *Making a 000 emergency calls* using their current method is 3.0 (Somewhat confident). The non-SSR users expressed the same level of confidence in both their current methods and SSR for this type of interaction with a median of 3.0 (Somewhat Confident). However, SSR users differ with a median of 2.0 (Not Confident) for their current methods increasing to a median of 4.0 (Confident) when using SSR.

The three respondents that scored confident or very confident were not from Australia, one indicating they used various types of relay services, the second indicating they used SSR and

landline. However, the third indicated they did not use a landline, but they would make emergency calls by landline, email, SMS or social networking sites. It is unclear whether this is making a call directly to emergency services or if it is indirect contact, for example putting a message on a social networking site for emergency assistance.

Interestingly, only six respondents indicated they use the landline independently, yet nine respondents indicated they would use the landline in an emergency. Another respondent highlighted the need for an SMS emergency service by stating, "If I'm out I can't text 000 on my mobile."

4.5   User Perspective of a Video-Assisted Speech-to-Speech Relay

This section addresses the second research question and presents the data regarding the respondents' use of VOIP and their perspectives on VAS. The first section of Table 7 presents data on how users perceive VOIP features, which might relate to features of VAS. The second presents the perceived usefulness of VAS in various types of interactions and the last section presents the perceived usefulness of VAS features.

The number of respondents varies between these three tables. The highest response rate is for Table 7, with 12 responses to the majority of the Likert scales. The next highest is in Table 8 having ten or eleven respondents to each scale. The least answered is in Table 9, *Perceived usefulness of VAS*, with only between seven and nine responses. All the N/A responses have been removed, as they do not add meaning.

4.5.1 Using VOIP

The first section of Table 7, *Using VoIP Features*, shows:

- eight respondents use VOIP to make calls to family and friends
- the voice capability is useful for nine respondents
- nine respondents prefer to use VoIP than a landline
- none of the respondents disagree it is useful for their communication partner to see them while they are communicating
- ten respondents indicated the instant messaging feature was useful for overcoming communication breakdowns

The following comment from one of the respondents suggests an enthusiasm to embrace

technology:

> "Do not use Skype or video chat only because I do not have technonlogy [sic] to do so at the moment. Maybe next year when I upggrade [sic] laptop!"

Table 7: Using VoIP features

	N	Agree	Neutral	Disagree
I rather use a landline than VoIP	11	1	1	9
I feel uncomfortable using a webcam	12	5	1	6
I use instant messaging for the whole conversation	12	5	3	4
I use my speech for most of the call	12	5	2	5
I use my voice or my SGD for the whole conversation	11	4	2	5
People understand what I am saying about as well as they understand me face to face	12	4	3	5
I use the speech output from my SGD	12	4	3	5
I often make VoIP calls to friends and family members	12	8	3	1
The voice capability is useful to me.	12	9	2	1
The instant messaging is useful when people are not understanding me	12	10	1	1
I find it useful for people to see me while I communicate with them	12	11	1	0

4.5.2 Perceived usefulness of VAS

The results in Table 8 show that the perceived usefulness of VAS in all the interaction types is

high with medians of 3.0 (Useful) and 4.0 (Very Useful). However, the three interaction types

least perceived as useful are *Talking with close family members*, *Talk with friends* and *Doing*

business, each having a median of 3.0 (Useful). The *Doing business* interaction type has the

lowest mean (2.78) because out of the nine who responded, one third did not perceive VAS to

be useful.

A respondent stated, "It is difficult to give definate [sic] answers when I0 [sic] have not used

the software. But after watching the video on how it can be used, I can see the potential [sic]

in the software". A focus group participant responded to the question regarding how

technology empowers with, "Technology gets more amazing and more accessible as we live...

i [sic] agree i [sic] love the idea of more video type of calls as it means we can use more

gestures as well as techno and that means quicker and more 'fluent' of course...".

Table 8: Perceived usefulness of VAS

	n	*x̃*	*sd*
Talking with close family members	8	3.0	0.76
Talking with friends	9	3.0	0.67
Ordering home delivery such as pizza	8	3.5	0.53
Booking a taxi	9	4.0	0.73
Speaking with your doctor (GP)	7	4.0	1.13
Contacting a call centre with important information	9	4.0	1.01
Making a complaint	9	4.0	1.12
Doing business	9	3.0	1.20
Making a 000 emergency call	8	4.0	1.07

n = Number of Responses; *sd* = Standard Deviation; *x̃* = Median;

Scale: 0 = N/A, 1 = Not At All Useful, 2 = Somewhat Useful, 3 = Useful, 4 = Very Useful

4.5.3   Usefulness of VAS features

Table 9 presents the findings of the respondents' perceived usefulness of VAS features. Eight

respondents indicated that they would probably find VAS useful. Seven indicated they would

use a VAS often. The respondents perceive the ability to see the Relay Officer and the Relay

Officer being able to see them as positive, with ten respondents in agreement. However, in

Table 7 (VoIP features), four agree and five disagree with the statement, 'People understand

what I am saying about as well as they understand me face to face.' Privacy was not considered an important issue by most respondents, with only two respondents in agreement that their privacy would be reduced by VAS and seven disagreeing. Most respondents would use the instant messaging facility to provide the Relay Officer prepared information for calls. Seven respondents would use all their communication methods while using VAS. However, only half of the respondents agreed VAS would be faster than their current methods of accessing telecommunications.

In responding to the question regarding their favourite method of accessing telecommunications a participant, who could not use SSR anymore because of losing the volume of his speech, expressed his hope for a VAS in the following comment:

> "When Video Assisted STS[13] becomes avaliavble[sic], and the operators can see my face, I hope that I will be able to make phone calls independently again without difficulty".

Table 9: Perceived usefulness of VAS features in making calls

	n	$\tilde{x}$	sd
My privacy would be reduced by using the video facility	11	4.00	1.29
The video facility would be distracting for me	11	4.00	1.22
I would probably not find a VAS useful	11	4.00	0.87
It would be faster to use VAS than my current methods of accessing telecommunications	10	2.00	1.35
I would use the instant messaging to provide the RO with pre-prepared information to assist in the call	10	2.00	1.20
I would be able to use all my methods of communication	11	2.00	1.19
Having the Relay Officer be able to see me will help me to communicate	11	2.00	0.90
Being able to show the Relay Officer things that I am talking about would be useful	11	2.00	0.87
I would probably use a VAS often	11	2.00	0.81
Being able to see the Relay Officer's face and body language will help me to communicate	11	2.00	0.67

n = Number of Responses; sd = Standard Deviation; $\tilde{x}$ = Median;

Scale: 1=Strongly Agree, 2=Agree, 3=Neither Agree or Disagree, 4=Disagree, 5=Strongly Disagree

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[13] The acronym used for Speech-to-Speech Relay is STS in the USA

4.6   Comparing Telecommunications Access Methods to types of call

This section presents the findings relating to the third research question, which compares the perspectives of respondents on the usefulness of their current methods of accessing telecommunications, with their perspectives on the usefulness of a VAS. The results of the previous two sections have been summarised in Figure 1, including the SSR results to assist in the interpretation. As discussed in Chapter Three, the Likert scales used in the current access methods and SSR questions differ from the scales used for VAS questions. This research considers the reported level of confidence in the use of telecommunications methods and the perceived usefulness of a potential alternative method. The first bar in Figure 1 indicates the median of expressed confidence of respondents in using their current access methods. The second is the median of the respondents' expressed confidence in using SSR and the third bar shows the median of the perceived usefulness of the respondents in using VAS for the various interaction types. The left axis shows confidence and the right usefulness.

In general, the respondents expressed a higher perception of the usefulness of using VAS in each of the interaction types than their expressed confidence in their current access methods and using SSR. The expressed perception of usefulness in using VAS for each of the interaction types is 4.0 (Very Useful), except for three interaction types, *Talking with close family members*, *Talking to friends* and *Doing business* having medians of 3.0 (Useful), and *Ordering home delivery* with a median of 3.5 (between Useful and Very Useful). The findings suggest the respondents would be likely to have greater confidence in using their current access methods than using VAS for the interaction types, *Talking with close family members* and *Talking to friends*.

Figure 1: Comparison of Users' Perceptions of Current Methods, SSR and VAS
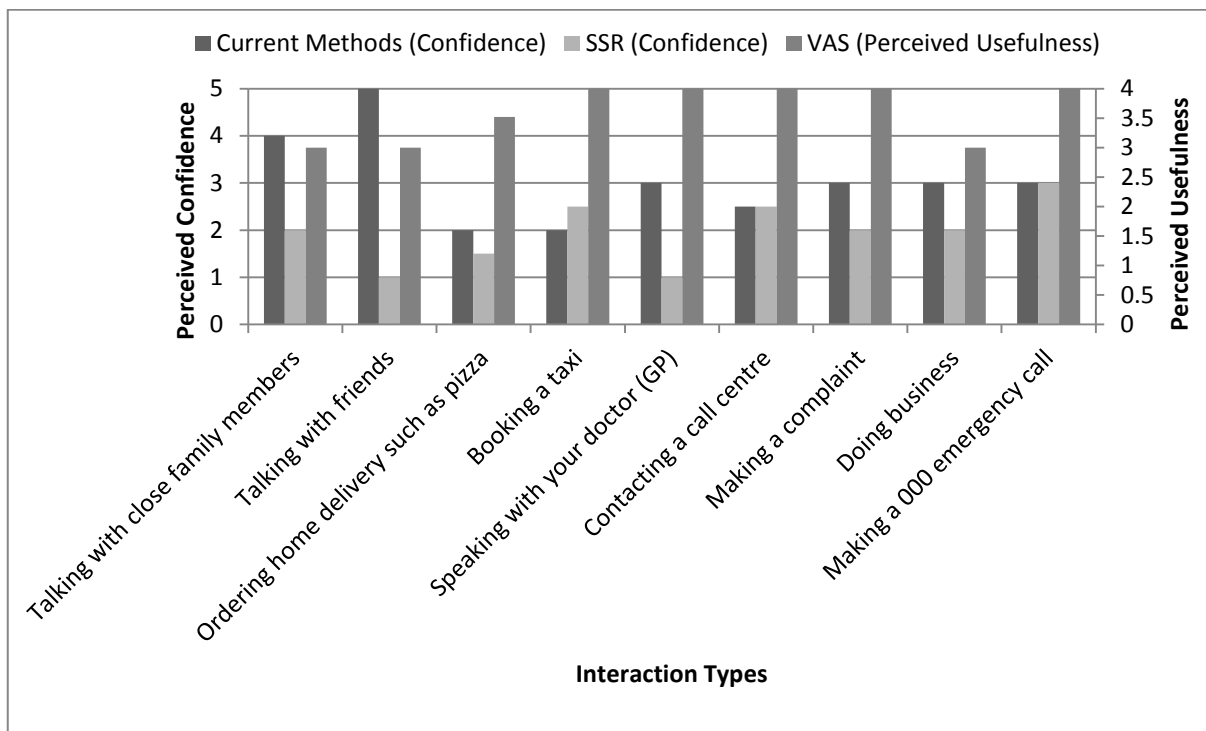
4.7 Conclusion

In summary, all of the respondents reported that they use email and social networking sites, and are frequent users of internet-based telecommunications methods, mostly text-based telecommunications (i.e. SMS, email, instant messaging and social networking sites). Many stated that they use multiple methods of accessing telecommunications, choosing different methods for various situations. Only half the respondents indicated they had experience of SSR and a third use SSR on a regular basis.

Most expressed greater confidence in their current telecommunications access methods than in using SSR. The respondents reported using their current methods for *Talking to their close family members* and *Talking with friends* express (or report) the most confidence.

Responding to the statements on their use of VoIP, the majority agreed communication is easier when their communication partner can see them and concur the instant messaging feature is useful for overcoming communication breakdowns. However, there was no

consensus among respondents about the statement regarding being uncomfortable using a webcam.

Most reported that they are positive towards the features of VAS with the majority of respondents agreeing a VAS would be useful and slightly fewer saying they would use VAS frequently. However, only half the respondents agreed VAS would be faster than their current methods of accessing telecommunications. Overall, the findings suggest that respondents have a higher perception of the usefulness of using VAS in each of the interaction types than their confidence in using their current telecommunications access methods except with friends and family. .

5   Discussion

5.1   Introduction

This chapter provides a detailed discussion and interpretation of the research results, viewing them through a Bourdieuian lens, and reviewing the results in the light of the literature. The findings are briefly summarised, followed by a discussion of the telecommunications access methods currently used by the respondents and their expressed perception of the usefulness of these methods, which includes use of Speech-to-Speech Relay (SSR). Respondents' perceived usefulness of Video Assisted Speech-to-Speech Relay (VAS) is discussed and compared with their perspectives on the usefulness of their current methods of accessing telecommunications. Issues and limitations of the research are then explored.

The current findings add to a growing body of literature on telecommunications for people with CCN. It is difficult to make conclusions based on the data collected due to the low number of respondents. Therefore, caution must be used in applying the findings to the general population of people with CCN.

The main findings of this study suggest people with CCN predominantly use text-based telecommunications including email, SMS and social networking sites. The results suggest the respondents are more confident in communication with familiar communication partners, such as family and friends. They expressed greater confidence in using their current methods with familiar communication partners than in using SSR. The perceived usefulness of VAS is high for each interaction type, but is lower with family and friends than with unfamiliar communication partners. The large difference between the confidence in SSR and the perceived usefulness of VAS is likely due to the extra modes of communication offered by VAS. The results indicate respondents might use a VAS more frequently than SSR.

5.2   Cohort

Although all respondents reported that they use an AAC device, many indicated they use multiple modes of communication ranging from natural speech to AAC to gestures/body language. This seems consistent with the research of Blackstone, Williams and Wilkins (2007), who suggest individuals with CCN use multiple modes of communication in their conversation. Some respondents reported that they use mainstream technology, such as mobile phones, as AAC devices, reinforcing the observations of DeRuyter et al. (2007) that AAC companies need to embrace emerging technologies.

The respondents indicated that they use a number of communication strategies and their primary communication method is not always AAC. These findings indicate that, as Bourdieu (1986) asserts, people choose the communication strategy which will attract the most capital. All the respondents in the survey indicated that they have an education greater than secondary education and a degree of digital literacy as they use technology, which is both assistive and mainstream. As mentioned in the Literature Review, digital literacy includes traditional literacy—reading and writing skills—and encompasses the skills required to access and manage online information (Bulfin & North, 2007; Poore, 2011).

The research assumes familiar communication partners are likely to be family and friends, and the other interaction types in the survey likely to be with unfamiliar communication partners. Thus, as previously noted, people with CCN are more likely to communicate with familiar communication partners (Collier, et al., 2010). In light of this, Bourdieu might suggest that being in the same social field they could share a similar habitus with these familiar communication partners enabling easier communication, leading to increased participation in their communities.

5.3   Current methods

There is very little literature on the kinds of telecommunications people with CCN actually use. To address this gap in the literature, the first research question investigated the types of telecommunications used by people with CCN and their perspectives on the usefulness of these methods. The results suggest the respondents use a range of telecommunications access methods with familiar partners. Unfortunately, the survey did not ask about the frequency of interaction types (e.g. *Talking with friends, Making a complaint*, *Ordering pizza* and *Doing business*). Respondents in this study reported that they use fewer telecommunications access methods and have less confidence with unfamiliar communication partners, predominantly using email and landline, supporting findings by Collier et al. (2010) that suggest people with CCN are less confident with unfamiliar communication partners.

The results seem to suggest the respondents use predominantly text-based telecommunications with familiar communication partners. However, as the survey did not investigate the frequency of use for the various types of telecommunications, it is not possible to ascertain which telecommunications access methods are predominantly used. Therefore, it is possible individuals with CCN use voice-based telecommunications methods more regularly than text-based. Respondents expressed more confidence in using their current methods than using SSR with familiar communication partners. A possible explanation is that when communicating with familiar partners they use an increased variety of communication strategies, which include text-based methods. Respondents expressed a lower level of confidence in communicating with people who are outside their 'field' of family and friends, supporting previous research by Collier et al. (2010). Surprisingly, the results of this study suggest respondents are more likely to use landline telephones to communicate with unfamiliar communication partners. This could be due to such diverse factors as affordability

(Eardley, et al., 2009), comprehension of dysarthric speech due to quality of sound[14] or usability of mobile phones (Nguyen, et al., 2008).

Willingness to embrace new technology is a common theme from the survey and focus group. One of the respondents highlights this willingness: "Do not use Skype or video chat only because I do not have technonlogy [sic] to do so at the moment. Maybe next year when I upggrade [sic] laptop!" Although the literature suggests new technology often creates additional barriers to people with disabilities (Eardley, et al., 2009; Goggin & Newell, 2007), this research has not investigated the physical barriers and affordability of telecommunications directly. However, the work of Nguyen et al. (2008) into accessibility of mobile phones for people with a disability could be extended to provide further understanding of the barriers to mobile telecommunications access for people with CCN.

The usage and confidence in using SSR indicated by the respondents is lower than expected. Respondents indicated a higher confidence in using their current methods than using SSR for all interaction types, with the exception of emergency calls. Confidence in making emergency calls received equal rating for both SSR and current methods. At the time of this study the majority of respondents were residing in countries where SSR is available (i.e. Australia and the United States of America). Although, SSR is only one of the telecommunications access methods available to individuals with CCN, and the sample size is too small to draw strong conclusions, the low frequency of use and degree of confidence in the service does highlight an area for further research, which should be of particular interest to service providers.

The most recent annual NRS Users Satisfaction Survey revealed that the service overall received a satisfaction level of 92 percent (ACE, 2011), which seems to be in contrast with the findings of this study. However, as discussed in the Literature Review, it is not possible to

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[14] Although the author is unaware of any research supporting this claim, it has been his experience over many years that voice quality for dysarthric speech is lower on mobile phones than on landlines.

isolate the satisfaction levels of SSR users since SSR calls makes up a small percentage of total calls made through the NRS. There could be numerous reasons for these findings. Firstly, based on previous experiences and preferences, some respondents' habitus might not incorporate a disposition towards this type of service; their habitus prompts them to use methods they already find more effective.

Secondly, a significant drop in the number of SSR users over recent years has to some extent been attributed to inadequate skills and abilities of Relay Officers in handling these types of relay calls (ACCAN, 2011). If people with CCN are not generally confident in communicating with unfamiliar communication partners (J. Ashford, Personal Communications, January 19, 2011), and as the Relay Officer is likely to differ from call to call, this could have an effect on caller confidence. In addition, a lack of awareness or understanding of the service could also explain the low use of SSR. Another possible explanation is the respondents' apparent preference for text-based telecommunications access methods.

It is essential for people with CCN to have access to emergency services (Bryen, 2010) and the findings of this study suggest the methods available for people with CCN to access these services may not be adequate. The respondents indicated they use a variety of text-based telecommunications access methods, highlighting the importance of implementing a text-based emergency call service (e.g. an SMS or internet-based emergency service) as discussed in the Literature Review. Australia has committed to ensuring people with disabilities have access to telecommunications services, which includes emergency services, by signing the United Nations Convention on the Rights of Persons with Disabilities (Morsillo & Ciavarra, 2010). Furthermore, ACCAN (2011) suggests SSR " ... has proven to be unreliable, and there are particular concerns regarding making 000 calls, because in times of stress, a user's speech may become less easily understood" (p. 19). Contrary to this assertion, and to the researcher's

expectations, the respondents indicated they have little confidence in SSR in their day-to-day use of telecommunications, yet a greater confidence in using SSR to make emergency calls. Interestingly, the respondents who do not use SSR indicated more confidence in making emergency calls via SSR, than those respondents who do use SSR.

5.4   Perspectives of Usefulness of VAS

The second research question investigated the users' perspectives of VAS. In general, the respondents rated the perceived usefulness of VAS higher than other methods of telecommunications. The survey asked respondents about their usage of VoIP, assuming VAS would operate over a VoIP platform, similar to a service such as Skype. As mentioned previously, all of the respondents have a degree of digital literacy. The general response was positive, with the majority using this form of telecommunications and many preferring VoIP to a landline telephone. Respondents indicated they often make VoIP calls to friends and family, thus building and maintaining their social networks. However, few respondents reported using VoIP for other interaction types. The respondents indicated that the features of audio, video and instant messaging are useful during conversations. The ability for partners to see each other during their calls and using instant messaging were identified as useful in overcoming communication breakdowns.

The reason for the VoIP usage being skewed towards familiar communication partners is unknown. One possible reason is VoIP calls are similar to face-to-face communication and people tend to be more comfortable communicating with familiar communication partners in face-to-face communication. Furthermore, it is possible the habitus of individuals with CCN suggests they would experience more communication difficulties in customer-to-business communication using VoIP, as the communication partner would be unfamiliar with their communication modes and less likely to successfully maintain or gain capital in the conversation.

The majority of respondents disagreed with the statement in using VoIP "people understand what I'm saying as well as they understand me face to face". This could be a result of poor design in the survey questions or could highlight issues with the quality of transmission when using VoIP, which may amplify the difficulties experienced by people with CCN. Dysarthric speech may be harder to understand by VoIP than face-to-face.

Fewer respondents answered the question on the perceived usefulness of VAS than indicated the usefulness of their current methods. This may be because the respondents have increased confidence responding to questions based on actual experiences than to speculative questions on the usefulness of a conceptual service. Those who did answer, expressed a higher level of perceived usefulness, yet expressed a lower level of perceived usefulness for communicating with familiar communication partners, similar to the trend for SSR. This could suggest the respondents are more likely to use a VAS to communicate with unfamiliar communication partners.

It is possible some potential users of VAS are uncomfortable using webcams. As the Relay Officer can see the person and their environment, the caller might feel the officer is intruding and there is an infringement of privacy. Two questions in the survey addressed this issue and the respondents indicated they do not consider privacy a critical issue. However, there is no consensus among respondents about the statement regarding being uncomfortable using a webcam.

One of the common themes emerging from these findings is a willingness to embrace new technology. The findings provide insight into the habitus of the respondents. This willingness to embrace new technology suggests that it is a beneficial strategy for attempting to increase social and cultural capital. In their social fields of family and friends, respondents perceive VoIP as a good mode of communication. Using VoIP allows them to continue choosing different communication strategies. Most are positive towards the features of VAS with the

majority of respondents agreeing a VAS would be useful and slightly fewer saying they would use VAS frequently.

5.5   Comparison of Telecommunications Access Methods

The third research question compared the perspectives of people with CCN on the usefulness of their current methods of accessing telecommunication with their perspectives on the usefulness of VAS. For most interaction types, the respondents expressed a higher perception of the usefulness of VAS than both their expressed confidence in their current access methods and using SSR. The perceived usefulness of VAS is high for all interaction types, yet it is slightly lower than ratings of current methods for familiar communication partners. Surprisingly, for the interaction type *Doing Business* respondents rate VAS slightly lower than for most interaction types, yet it still rates higher than their current access methods.

The findings suggest that the respondents would use VAS similarly to SSR; they will use it more to communicate with unfamiliar communication partners. However, it is interesting they rate it much higher than their current methods and SSR. Bourdieu may argue the respondents seem to share a similar habitus, which views VAS as an improved communication strategy to assist them to accumulate social and cultural capital. This accumulation of capital provides the respondents with increased social positioning in the fields in which they participate. Therefore, this increases their influence in their own social networks thus gaining empowerment in their lives.

It would be easy to assume the video feature is the reason behind the high-perceived usefulness of VAS, as both the Relay Officer and the caller with CCN can see each other. However, the instant messaging feature could be an attribute to the high-perceived usefulness of VAS due to the respondents' apparent preference for text-based telecommunication access methods.

6   Conclusion

6.1   Findings of the research

This research set out to investigate the telecommunications access methods that assist to empower individuals with CCN to participate fully in society. Other researchers have used a Bourdieuian lens to investigate the dynamic notions of disability and social inequality that are experienced in the lives of people with disabilities (Björnsdóttir & Jóhannesson, 2009; Edwards & Imrie, 2003; Simmons, et al., 2008). Likewise, this thesis uses the theoretical lens of Bourdieu's concepts—habitus, field and capital—to explore the experience of people with CCN using telecommunications in an effort to increase their social and cultural power, and thus gain greater control over their lives.

The Literature Review identified that there is very little literature on what kinds of telecommunications people with CCN actually use. Thus, this study set out to address this gap in the literature and to gain insight into the types of barriers people with CCN face in accessing telecommunications to accumulate capital. The first research question investigated the types of telecommunications used by people with CCN and their perspectives on the usefulness of these methods. The second question investigated their perceived usefulness of VAS. Lastly, the research compared the respondents' perspectives on the usefulness of these access methods.

The findings from this research highlight several issues surrounding the barriers facing people with CCN to accumulate social capital via telecommunications. Respondents indicated they use a number of communication strategies in different interactions, AAC is not always their primary communication method, and they use a range of telecommunications access methods in their communication. This accords with the notion that people choose the communication strategy which will attract the most capital (Bourdieu, 1986). The high use of text-based

telecommunication in the cohort (e.g. email, SMS and instant messaging) highlights the need for sufficient education to be literate, not just in the traditional sense but also in the digital sense. Surprisingly, the respondents indicated low usage of SSR and the findings suggest the types of telecommunication the respondents use with familiar communication partners are predominantly text-based.

 Respondents expressed a lower level of confidence in communicating with people who are outside their field of family and friends, supporting previous research by Collier et al. (2010). With unfamiliar communication partners, respondents are more likely to use landline telephones and email. Respondents indicated a higher confidence in using their current methods than using SSR for all interaction types with the exception of emergency calls. The usage and confidence in using SSR indicated by the respondents was lower than expected. There is a similar trend of perceived confidence in using SSR and VAS, a lower confidence with family and friends than with unfamiliar communication partners. However, there is a large difference between the confidence in SSR and the perceived usefulness of VAS, which is likely due to the extra modes of communication offered by VAS. The results indicate respondents might use a VAS more frequently than SSR. This could suggest the respondents are more likely to use a VAS to communicate with unfamiliar communication partners.

In addition, it is important to be able to communicate in the event of emergency. It is essential for all to have access to emergency services, including people with CCN (Bryen, 2010). The findings of this study suggest the methods available to access these services may not be adequate for people with CCN.

In summary, the findings from this study suggest that the respondents predominantly use text-based telecommunications with familiar communication partners and have a willingness to embrace new technology. Respondents reported confidence communicating with familiar communication partners, which lowered when interacting with unfamiliar partners. They

reported a preference for using their current access method with familiar communication partners, as opposed to using SSR, but for interacting with unfamiliar communication partners, they prefer to use landline telephones or email. SSR is one of many ways people with CCN can compete more fairly for social capital using telecommunications; however, the reported usage and confidence was lower than expected. Furthermore, the study reveals the methods available for people with CCN to access emergency services might not be adequate.

As DeRuyter et al. (2007) argue, people with CCN require more than face to face communication; they also require access to telecommunications in order to fully participate in their communities. In Bourdieuian terms, this is the need for communication to participate and position oneself in the social field (Bourdieu, 1986). The results of this study indicate respondents, in participating and positioning in social fields, might use a VAS more frequently than SSR and this perceived usefulness is likely due to the extra modes of communication offered by VAS.

6.2 Limitations of the research

6.2.1 Recruitment Issues

As noted in the Methodology section, the original proposed research design was modified to address the difficulties experienced in recruiting participants to the study. Despite these modifications, it was still difficult to recruit participants. The research attracted respondents who all indicated having greater than secondary education and expressed confidence in using technology, raising the question of how representative the sample is of the general population of people with CCN. The results may be more representative of this particular type of cohort than the general population of people with CCN. Therefore, the findings of this research are difficult to generalise for the broader population of people with CCN.

6.2.2   Survey Design Issues

There were several other limitations encountered in conducting this study. One such design issue was the inclusion criteria for respondents, as it did not fully restrict the participation criteria to only people with CCN. Nevertheless, through analysing the data the researcher believes the surveys deemed useable are from respondents with CCN.

In the design of the survey, a distinction between participants' current telecommunication method and their use of SSR was not explicit; therefore, it could be argued the confidence in both categories could be seen as unreliable.

Lastly, the lower response and higher level of perceived usefulness of VAS could potentially be attributed to improperly designed or poorly worded survey questions. The bias of the researcher toward the usefulness of VAS could have contributed to the respondents expressing the high level of perceived usefulness of VAS.

The researcher acknowledges he has potential bias towards relay services, due to his work with the Australian provider of the National Relay Service, Australian Communication Exchange, as part of the AAC community and as a user of SSR. This potential bias may have prevented the researcher from analysing and reporting the findings in an objective manner. However, his knowledge and experience of the field could have enriched the findings of this study.

6.3   Recommendations for future work

The findings of this study have highlighted several areas further research is required. There is a lack of research into the effectiveness of SSR and the competencies needed by Relay Officers in order to support successful communication. Areas for further research could include the usefulness of such a service, the barriers preventing potential users from using the service and how the presence of a third party, the Relay Officer, affects the communication between the caller and recipient.

Respondents indicated they have little confidence in SSR in their day-to-day use of telecommunications, and yet they expressed equal rating in both SSR and their current methods with making emergency calls. Research suggests SSR is not reliable for calling emergency services as in times of stress the intelligibility of people's speech can decrease (ACCAN, 2011). Further research to explore this apparent contradiction between the findings of this study and previously reported research would be of value.

Both the video and the instant messaging features could be contributing to the high perceived usefulness of VAS. It would be valuable to investigate the relative contribution of either or both of these to this perception. This would contribute to the development of VAS and telecommunications for people with CCN.

Given the findings of a high level of perceived usefulness of a VAS service expressed by the respondents, there is a need for further research aimed at investigating the potential of a VAS to enhance the participation of people with CCN in society. Such future research could include a more extensive survey of potential users. Following the survey, a limited trial of the service could be implemented based on the results of the survey and suggestions for improvements could be used in a subsequent pilot project. The pilot could be evaluated through a longitudinal study designed to measure the extent to which the VAS contributed to a change in the level of social participation and perceived social capital reported by CCN users. Such a study would shed further light on the potential of VAS and help to determine if such a service can be effective in assisting people with CCN to maintain and gain social capital within their various social fields.

The current findings contribute to a growing body of literature on telecommunications for people with CCN. Due to the low number of survey respondents and participants in the online focus group, it is difficult to make conclusions based on the data collected. Therefore, caution must be applied, as the findings may not be transferrable to the general population of people

with CCN. However, this research has demonstrated that people with CCN are using a variety of telecommunications access methods to participate in society and to accumulate social capital, and VAS could potentially enhance their access to telecommunications. Thus, this study has highlighted the need for further research into the enhancement of communication strategies using telecommunications, which increase the return of social capital available to people with CCN.

7   Appendices

Appendix A: Recruitment Email

Re: The Sound of a Smile: A Telecommunications Research Project For AAC Users

Hello,

Are you an AAC user? Do you ever use the telephone, send text messages or emails, use text chat or even video calls? If so, you might be interested in being part of a research project exploring various telecommunications services.

I'm Darryl Sellwood from Adelaide, South Australia. I'm looking for people who use Alternative and Augmentative Communication (AAC) to take part in a survey and online discussion. This project is a study into the current methods that users of augmentative and alternative communication (AAC) employ for accessing telecommunications and their perspectives on the usefulness of a Video Assisted Speech to Speech Relay Service (VAS).

This project is part of my Honours research at the University of South Australia. As an AAC user, I understand many of the challenges people with complex communication needs (CCN) face in accessing telecommunications. As a computer science graduate with experience in the telecommunications field, I have a broad perspective on both user and technical issues. The project has ethics approval from the Division of Education, Arts and Social Sciences Human Research Ethics Committee of the University of South Australia.

I am looking for people willing to participate in an online survey comparing methods of accessing telecommunications and exploring the possible usefulness of a Video-Assisted Speech-to-Speech Relay (VAS). You will also be invited to participate in an online discussion group (focus group) which will run for two weeks. The following time commitments will be involved:

· The online survey will require approximately twenty (20) to thirty (30) minutes of your time and will be open until the 17th January 2011.

· The focus group will require between ten (10) minutes and one (1) hour each week, depending on how much you wish to contribute, for an additional two weeks commencing on the 30th November.

If you meet al.l the criteria below and can spare this time during the project period, please visit the survey at http://www.surveymonkey.com/s/The_Sound_of_a_Smile. Please do not hesitate to email me requesting more information at seldj001@mymail.unisa.edu.au.

Participants must meet al.l the following criteria: Participants criteria: (a) be over 18 years old, (b) use AAC device, (c) have a level of literacy adequate to complete the survey and participate in the online focus group and (d) have the ability to provide informed consent.

I hope you can be part of this exciting research project into access to telecommunications for people with CCN.

Regards,

Darryl Sellwood BCIS
Researcher

Contact Information

This project has been approved by the University of South Australia's Human Research Ethics Committee. If you have any ethical concerns about the project or questions about your rights as a participant please contact the Executive Officer of this Committee, Tel: +61 8 8302 3118; Email: Vicki.allen@unisa.edu.auu

Supervisor's name & contact details:

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Appendix B: A copy of the survey

Participant Survey

1. Introduction

Project title

The sound of a smile: user perspectives of Video-Assisted Speech-to-Speech Relay for people with Complex Communication Needs

Please read the Participant Information Sheet (Opens in new tab)

* 1. Do you qualify to take part in this research project?

You are:
(a) be over 18 years old,
(b) use AAC device and
(c) have a level of literacy adequate to complete the survey and participate in the online focus group.

- Yes
- No

Participant Survey

* **2. Do you agree to the following statements?**

  • You have read the Participant Information Sheet.

  • You understand the nature and purpose of the research project and your involvement in it.

  • You understand that you may withdraw from the research project at any stage and that this will not affect your status now or in the future.

  • You understand that while information gained during the study may be published, you will not be identified and your personal results will remain confidential.

  • You understand that information will be captured electronically using an internet survey form and a discussion board.

  • You understand that the researcher cannot guarantee the confidentiality or anonymity of material transferred by email or the internet.

  • You understand that the data will be analysed using a password-protected computer and then stored on digital media and held by the University of South Australia for five years.

  • You agree to participate in this research project.

  . Yes   . No

2. About You

In this section, you will be asked about yourself.

Participant's responses will be kept confidential and all identifying information will be removed as soon as possible. Participants will not be identified in published material. However, the researcher cannot guarantee the confidentiality or anonymity of material transferred by email or the internet.

* **1. Your age**

  . 18 - 24 years

  . 25 - 34 years

  . 35 - 44 years

  . 45 - 54 years

  . 55 + years

Participant Survey

* 2. In which country do you live?

Country [▼]

* 3. Highest level of education you have completed

- Primary school (up to grade 8)
- High school
- Diploma (eg TAFE or 2 year college)
- Tertiary degree
- Post graduate studies (ie Masters or PhD)

* 4. Your Primary Disability

* 5. Your Gender

- Female
- Male

* 6. Your AAC device

The type of AAC device/s you use [   ]

Your preferred method of accessing your AAC device (Direct selection, Head pointing, Right foot with trackball, etc.) [   ]

7. Your primary method(s) of communicating

- Natural speech
- Gestures/body language
- Sign language/finger spelling
- AAC device

Other (please specify)
[   ]

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Participant Survey

✱ 8. Please rate the following statements relating to your experience with technology

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
My friends and family ask me for advice about their computers and mobile phones	·	·	·	·	·
I'm just learning to use the computer	·	·	·	·	·
I easily learn how to use new programs on the computer	·	·	·	·	·
I am a computer professional	·	·	·	·	·
New technology frightens me	·	·	·	·	·
I always go out and buy the latest gadgets	·	·	·	·	·

3. Current telecommunication access

In this section you will be asked to rate the likelihood of successfully using a phone with or without speech to speech relay for various types of phone calls.

1. What kind of telecomunications do you use?

	Independently use	Use with assistance	Don't use
Landline Telephone	·	·	·
Email	·	·	·
Mobile/cellular phone (Speech)	·	·	·
Mobile/cellular phone (SMS)	·	·	·
VOIP (eg Skype)	·	·	·
Text chat	·	·	·
Video call	·	·	·
Social Networking, eg Facebook	·	·	·

Other (please specify)

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2. Which kind of relay service do you use in making phone calls?

- Internet Relay Calls (IP Relay)

- Speak and Listen (Speech-to-Speech Relay)

- Speak and Read (Voice Carry Over Relay Service)

- Type and Read (TTY Relay Calls)

- Type and Listen (Hearing Carry Over Relay Service)

- None

Other (please specify)

3. What kind of telecommunications methods do you use in the following contexts? (Not face to face)

	Landline Telephone	Email	Mobile calls	SMS	VOIP (eg Skype)	Text chat	Video call	Social Networking, eg Facebook
Talking with close family members	·	·	·	·	·	·	·	·
Talking with friends	·	·	·	·	·	·	·	·
Ordering home delivery such as pizza	·	·	·	·	·	·	·	·
Booking a taxi	·	·	·	·	·	·	·	·
Speaking with your doctor (GP)	·	·	·	·	·	·	·	·
Contacting a call centre with important information	·	·	·	·	·	·	·	·
Making a complaint	·	·	·	·	·	·	·	·
Doing business	·	·	·	·	·	·	·	·
Making a 000 emergency call	·	·	·	·	·	·	·	·

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Participant Survey

*4. How confident are you in making the following types of phone calls using your current methods? (Without assistance)

	Wouldn't attempt	Not confident	Somewhat confident	Confident	Very Confident	N/A
Talking with close family members	·	·	·	·	·	·
Talking with friends	·	·	·	·	·	·
Ordering home delivery such as pizza	·	·	·	·	·	·
Booking a taxi	·	·	·	·	·	·
Speaking with your doctor (GP)	·	·	·	·	·	·
Contacting a call centre with important information	·	·	·	·	·	·
Making a complaint	·	·	·	·	·	·
Doing business	·	·	·	·	·	·
Making a 000 emergency call	·	·	·	·	·	·

Comments

4. Speech to Speech Relay Service

Speech to speech relay services have been available in a number of countries throughout the world. In a speech to speech relay call, a trained Relay Officer (known in the USA as a communication assistant) is on the line to assist with communication. This section explores your experience with speech to speech relay.

1. How long have you used a speech to speech relay service?

- Never used
- Less than 6 months
- 6 months to one year
- 1-3 years
- 3-5 years
- 5-10 years

*2. How often do you use spech to speech relay?

- Never
- 1-6 times per year
- Monthly
- Weekly
- Daily

3. How confident would you be making the following types of call using a Speeech to Speech relay service?

	Wouldn't attempt	Not confident	Somewhat confident	Confident	Very confident	N/A
Talking with close family members	·	·	·	·	·	·
Talking with friends	·	·	·	·	·	·
Ordering home delivery such as pizza	·	·	·	·	·	·
Booking a taxi	·	·	·	·	·	·
Speaking with your doctor (GP)	·	·	·	·	·	·
Contacting a call centre with important information	·	·	·	·	·	·
Making a complaint	·	·	·	·	·	·
Doing business	·	·	·	·	·	·
Making a 000 emergency call	·	·	·	·	·	·

5. The Concept of Video Assisted Speech to Speech Relay

This section talks about the concept of a Video Assisted Speech to Speech Relay service. Before answering this section please watch the "Introduction To VAS" online video.
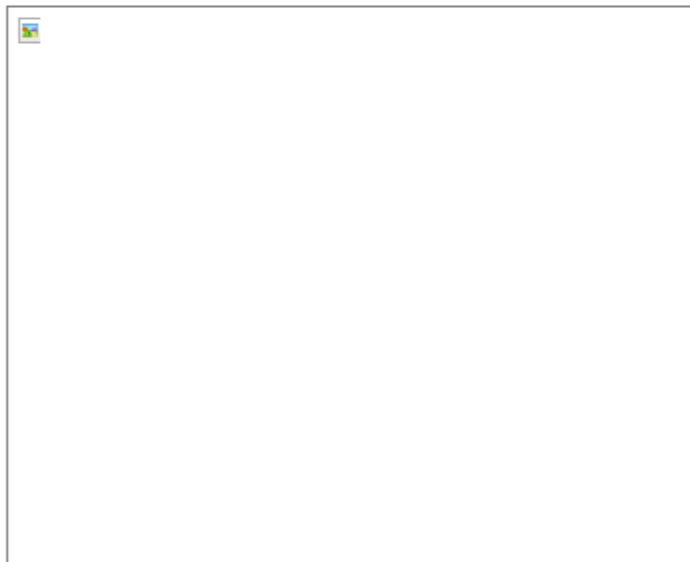
This section is to gather your impressions of a VAS before you have used it.

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Participant Survey

1. Please rate the following statements regarding making VoIP calls.

VoIP calls refers to calls made using software such as Skype, Yahoo Messenger, MSN Messenger, etc. These calls have voice, video and text instant messaging.

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
I often make VoIP calls to friends and family members	·	·	·	·	·
The voice capability is useful to me.	·	·	·	·	·
I use my speech for most of the call	·	·	·	·	·
People understand what I am saying about as well as they understand me face to face	·	·	·	·	·
I rather use a landline than VoIP	·	·	·	·	·
I use the speech output from my SGD	·	·	·	·	·
I find it useful for people to see me while I communicate with them	·	·	·	·	·
I feel uncomfortable using a webcam	·	·	·	·	·
The instant messaging is useful when people are not understanding me	·	·	·	·	·
I use instant messaging for the whole conversation	·	·	·	·	·
I use my voice or my SGD for the whole conversation	·	·	·	·	·

Please feel free to add further comments.

2. VAS type services have been available in Finland and some trials have been conducted in the USA. Have you used a VAS-type service?

· No

· Yes

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Participant Survey

3. How useful do you think you would find VAS in making the following types of call?

	Not at all useful	Somewhat useful	Useful	Very useful	N/A
Talking with close family members	·	·	·	·	·
Talking with friends	·	·	·	·	·
Ordering home delivery such as pizza	·	·	·	·	·
Booking a taxi	·	·	·	·	·
Speaking with your doctor (GP)	·	·	·	·	·
Contacting a call centre with important information	·	·	·	·	·
Making a complaint	·	·	·	·	·
Doing business	·	·	·	·	·
Making a 000 emergency call	·	·	·	·	·

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4. Thinking about how a VAS would work, please rate the following statements.

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Having the Relay Officer be able to see me will help me to communicate	-	-	-	-	-
Being able to see the Relay Officer's face and body language will help me to communicate	-	-	-	-	-
I would use the instant messaging to provide the RO with pre-prepared information to assist in the call	-	-	-	-	-
I would probably not find a VAS useful	-	-	-	-	-
I would probably use a VAS often	-	-	-	-	-
Being able to show the Relay Officer things that I am talking about would be useful	-	-	-	-	-
The video facility would be distracting for me	-	-	-	-	-
My privacy would be reduced by using the video facility	-	-	-	-	-
I would be able to use all my methods of communication	-	-	-	-	-
It would be faster to use VAS than my current methods of accessing telecommunications	-	-	-	-	-

Please feel free to add further comments.

6. Online Focus Group

Thank you for taking part in this survey. This research project also includes a three week online focus group, to discuss telecommunications for AAC users in more depth, which is optional.

Please indicate whether you would like to take part in the second phase, and if so please provide the following information.

* 1. Would you like to participate in the online focus group?

- Yes

- No

7. Online Focus Group Details

Participant Survey

Thank you for choosing to participate in the online focus group. Aliases will be used to protect your identity and provide anonymity. Please do not use your real name, as this would violate university rules. If by chance two people choose the same alias, the researcher will email them both asking them to choose new aliases.

Your email address will be kept confidential by the researcher, and only used by the researcher for communication with you during this project.

* 1. Please enter your desired alias. Tip: choose a short one, as it will be your login name.

The alias should be between 4 and 12 letters long.

* 2. Please enter your email address.

8. Thank You

Congratulations, you have reached the end of the survey.

Thank you for your time.

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Appendix C: Focus Group Questions

Question 1: Favourite Food

"Welcome to the online focus group. This topic is to allow you see how the forum

works and try it out.

In this topic, please let us know your favourite food.

Please remember, to help maintain your privacy, please do not post personal

information on the forum (e.g. your surname, phone number, email address etc.)."

Question 2: Favourite Telecommunication Method

"In the survey you were asked what were your current methods of accessing

telecommunications, such as landline, mobile, email and social networking sites.

Please share what your favourite method is and how it helps you on a day to day

basis."

Question 3: Does having access to telecommunications empowers?

"Does having access to telecommunications, such as telephones, emails, Relay

Services and social networking sites (ie. Facebook) give you more power to do what

you want to do in your daily life? Please explain why or why not?

Please feel free to use dot-points if it is easier."

Question 3: Personal experiences of successful communication:

"I would like to hear personal stories where using telecommunications has helped in

your daily life. Can you remember a time you realised that telecommunications were

really valuable in helping you to be a part of your community?

Note: You may find the use of dot-points easier. "

Question 5: Video Hits - What's so promising of Video-Assisted Speech-to-Speech Relay (VAS)?

"The survey to seem to suggest that there is more confident in the usefulness of a VAS than is the usefulness of traditional speech to speech relay.

- Why do you think this is?

- What features of VAS do you think account for this increase in confidence?

Before answering these questions you might want to watch the "Introduction To VAS" online video from the survey again to remember how a VAS can works."

8   Reference List

ACCAN. (2011). Inclusive Communications: Submission to the Review of Access to Telecommunication Services by People with Disability, Older Australians and People Experiencing Illness. 84. Retrieved from http://www.dbcde.gov.au/__data/assets/word_doc/0008/139706/ACCAN_submission_National_Relay_Service_Review_2011.doc

ACE. (2011). Annual Report for the year ended 30 June 2011. Brisbane: Australian Communication Exchange Ltd.

ACMA. (2010a). ACMA Annual Report 2009-10   Retrieved from http://www.acma.gov.au/WEB/STANDARD/pc=PC_312295

ACMA. (2010b). The National Relay Service Performance Report 2008-09. Retrieved from http://www.acma.gov.au/webwr/_assets/main/lib100096/nrs_report_2008-09.pdf

ACMA. (2010c). Universal Service Obligation Retrieved 3 April, 2011, from http://www.acma.gov.au/scripts/nc.dll?WEB/STANDARD/1001/pc=PC_2491

ACMA. (2011). The National Relay Service Performance Report 2009-10   Retrieved from http://www.acma.gov.au/webwr/_assets/main/lib100096/nrs_report_2009-10.pdf

Alant, E., Bornman, J., & Lloyd, L. (2006). Issues in AAC research: How much do we really understand? *Disability & Rehabilitation, 28*(3), 143-150.

Alleman, J., Rappoport, P., & Banerjee, A. (2010). Universal service: A new definition? *Telecommunications Policy, 34*(1-2), 86-91. doi: 10.1016/j.telpol.2009.11.009

Alm, N., & McGregor, A. (2006, 5 August 2006). *An AAC user as part of a research team.* Paper presented at the Conference Proceedings -- International Society for Augmentative & Alternative Communication, Dusseldorf, Germany.

Balandin, S., Berg, N., & Waller, A. (2006). Assessing the loneliness of older people with cerebral palsy. *Disability & Rehabilitation, 28*(8), 469-479. doi: 10.1080/09638280500211759

Barnes, C. (1992). Qualitative Research: Valuable or Irrelevant? *Disability & Society, 7*(2), 115-124. doi: 10.1080/02674649266780151

Barnes, C. (2003). What a Difference a Decade Makes: Reflections on doing 'emancipatory' disability research. *Disability & Society, 18*(1), 3 - 17. doi: 10.1080/713662197

Barnes, C., Mercer, G., & Shakespeare, T. (2010). The Social Model of Disability In A. Giddens & P. W. Sutton (Eds.), *Sociology: introductory readings* (pp. 162-169). Cambridge: Polity.

Björck-Åkesson, E., Granlund, M., Light, J., & McNaughton, D. (2000). *Goal setting and problem solving with AAC users and families.* Paper presented at the International Society for Augmentative & Alternative Communication, Washington D.C.

Björnsdóttir, K., & Jóhannesson, I. (2009). People With Intellectual Disabilities in Iceland: A Bourdieuean Interpretation of Self-Advocacy. *Intellectual and Developmental Disabilities, 47*(6), 436-446. doi: 10.1352/1934-9556-47.6.436

Blackstone, S. W., Williams, M. B., & Wilkins, D. P. (2007). Key principles underlying research and practice in AAC. *AAC: Augmentative & Alternative Communication, 23*(3), 191-203.

Bourdieu, P. (1986). The Forms of Capital (R. Nice, Trans.). In J. E. Richardson (Ed.), Handbook for Theory and Research for the Sociology of Education (pp. 47-58): Greenword Press. Retrieved from http://econ.tau.ac.il/papers/publicf/Zeltzer1.pdf.

Bourdieu, P. (1990). *In other words: essays towards a reflexive sociology*. California: Stanford University Press.

Bourdieu, P., & Wacquant, L. J. D. (1992). *An Invitation to Reflexive Sociology*. Chicago Polity.

Brunson, J. L. (2009). The practice and organization of sign language interpreting in video relay service: An institutional ethnography of access. *Dissertation Abstracts International, 69*(8-A), 33-43.

Bryen, D. N. (2008). Vocabulary to support socially-valued adult roles. *AAC: Augmentative & Alternative Communication, 24*(4), 294-301.

Bryen, D. N. (2010). Communication in times of natural or man-made emergencies: the potential of speech-generating devices. *International Journal of Emergency Management, 7*(1), 17-28.

Bulfin, S., & North, S. (2007). Negotiating Digital Literacy Practices Across School and Home: Case Studies of Young People in Australia. *Language & Education: An International Journal, 21*(3), 247-263.

COAT. (2011). Leading COAT Affiliates Support Internet-Enabled Relay for People with Speech Disabilities | Coalition of Organizations for Accessible Technology Retrieved 1 November 2011, from http://www.coataccess.org/node/10070

Collier, B., Mcghie-Richmond, D., & Selfa, H. (2010). Exploring Communication Assistants as an Option for Increasing Communication Access to Communities for People who use Augmentative Communication. *Augmentative and Alternative Communication, 26*(1), 48-59.

Conroy, S., Senator. (2010). Address to CommsDay Summit 2010 Retrieved 24 January, 2011, from http://www.minister.dbcde.gov.au/media/speeches/2010/006

Cooper, L., Balandin, S., & Trembath, D. (2009). The Loneliness Experiences of Young Adults with Cerebral Palsy who use Alternative and Augmentative Communication. *AAC: Augmentative & Alternative Communication, 25*(3), 154-164.

Danieli, A., & Woodham, C. (2005). Emancipatory Research Methodology and Disability: A Critique. *International Journal of Social Research Methodology, 8*(4), 281-296.

Dattilo, J., Estrella, G., Estrella, L., Light, J., McNaughton, D., & Seabury, M. (2008). "I have chosen to live life abundantly": Perceptions of leisure by adults who use Augmentative and Alternative Communication. *Augmentative & Alternative Communication, 24*(1), 16-28.

DeRuyter, F., McNaughton, D., Caves, K., Bryen, D. N., & Williams, M. B. (2007). Enhancing AAC connections with the world. *AAC: Augmentative & Alternative Communication, 23*(3), 258-270.

Eardley, T., Bruce, J., & Goggin, G. (2009). Telecommunications and Community Wellbeing: a review of the literature on access and affordability for low-income and disadvantaged groups *SPRC Report* (Vol. 9). Sydney: Social Policy Research Centre, University of New South Wales.

Edwards, C., & Imrie, R. (2003). Disability and Bodies as Bearers of Value. *Sociology, 37*(2), 239-256.

Elman, R. J. (2001). The Internet and aphasia: Crossing the digital divide. *Aphasiology, 15*(10/11), 895-899. doi: 10.1080/02687040143000267

emergencySMS. (2009). emergencySMS - SMS to the emergency services Retrieved 14 January, 2011, from http://www.emergencysms.org.uk/index.php

Erickson, K., & Sachse, S. (2010). Reading Acquisition, AAC and the Transferability of English Research to Languages with More Consistent or Transparent Orthographies. *Augmentative and Alternative Communication, 26*(3), 177-190. doi: 10.3109/07434618.2010.505606

Federal Communication Commission. (2010). National Broadband Plan: Chapter 9 - Adoption and Utilization Retrieved 4 June, 2010, from http://www.broadband.gov/plan/9-adoption-and-utilization/

Goggin, G., & Newell, C. (2003). *Communicating Disability: What's the Matter with Internet Studies?* Paper presented at the ANZCA Conference Brisbane http://www.hss.bond.edu.au/ANZCA/papers/GGogginCNewellPaper.pdf

Goggin, G., & Newell, C. (2007). The Business of Digital Disability. *The Information Society, 23*(3), 159-168. doi: 10.1080/01972240701323572

Harrison, P. R. (1993). Bourdieu and the Possibility of a Postmodern Sociology. *Thesis Eleven, 35*(1), 36-50. doi: 10.1177/072551369303500104

Higginbotham, D. J., Shane, H., Russell, S., & Caves, K. (2007). Access to AAC: Present, past, and future. *Augmentative and Alternative Communication, 23*(3), 243-257. doi: 10.1080/07434610701571058

Hughes, B. (2002). Disability and the Body. In C. Barnes, M. Oliver & L. Barton (Eds.), *Disability studies today* (Vol. Illustrated, pp. 58-97). Cambridge: Wiley-Blackwell.

ITU. (2010). The World in 2010: ICT Fact and Figures International Telecommunication Union, (pp. 8). Retrieved from http://www.itu.int/ITU-D/ict/material/FactsFigures2010.pdf

ITU. (2011). Measuring the Information Society 2011 (pp. 156). Retrieved from

http://www.itu.int/ITU-

D/ict/publications/idi/2011/Material/MIS_2011_without_annex_5.pdf

Kitchin, R. (2002). Towards Emancipatory and Empowering Disability Research: Reflections on Three

Participatory Action Research Projects Retrieved May 1, 2009, from

http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/87418679FAE58B0E80256F02004753E9

/$File/ParA3.htm

McNaughton, D., & Bryen, D. N. (2007). AAC technologies to enhance participation and access to

meaningful societal roles for adolescents and adults with developmental disabilities who

require AAC. *AAC: Augmentative and Alternative Communication, 23*(3), 217-242.

McNaughton, D., Light, J., & Arnold, K. (2002). 'Getting your wheel in the door': successful full-time

employment experiences of individuals with cerebral palsy who use Augmentative and

Alternative Communication. *Augmentative and Alternative Communication, 18*(2), 59-76. doi:

10.1080/07434610212331281171

McNaughton, D., Light, J., & Groszyk, L. (2001). "Don't give up": Employment experiences of

individuals with amyotrophic lateral sclerosis who use augmentative and alternative

communication. *Augmentative and Alternative Communication, 17*(3), 179-195. doi:

10.1080/aac.17.3.179.195

McNaughton, D., Symons, G., Light, J., & Parsons, A. (2006). "My dream was to pay taxes": The self-

employment experiences of individuals who use augmentative and alternative

communication. *Journal of Vocational Rehabilitation, 25*(3), 181-196.

Mercer, G. (2002). Emancipatory DIsability Research. In C. Barnes, M. Oliver & L. Barton (Eds.),

Disability studies today (Vol. Illustrated, pp. 228-249): Wiley-Blackwell.

Mercieca, D., & Mercieca, D. (2010). Opening Research to Intensities: Rethinking Disability Research

with Deleuze and Guattari. *Journal of Philosophy of Education, 44*(1), 79-92. doi:

10.1111/j.1467-9752.2010.00745.x

Migliorino, P. (2011). Digital Technologies Can Unite but Also Divide: CALD Communities in the Digital

Age. [Online]. *Australasian Public Libraries and Information Services, 24*(3), 107-110.

Morsillo, R. (2011). One down, two to go: public policy in service of an available, affordable and

accessible National Broadband Network for people with disability. *Telecommunications*

Journal of Australia, 61(2), 1-13.

Morsillo, R., & Ciavarra, B. (2010). Telstra Submission - Productivity Commission Public Inquiry into

Long-Term Disability Care and Support. (16 August 2010). Retrieved from

http://www.pc.gov.au/__data/assets/pdf_file/0008/101321/sub0292.pdf

Nguyen, T., Garrett, R., Downing, A., Walker, L., & Hobbs, D. (2004). Research into Telecommunications Options for People with Physical Disabilities. In D. Zhang & M. Mokhtari (Eds.), *Towards a Human-Friendly Assistive Environment* (2nd ed., pp. 57-77). Amsterdam: IOS Press.

Nguyen, T., Garrett, R., Downing, A., Walker, L., & Hobbs, D. (2008). An interfacing system that enables speech generating device users to independently access and use a mobile phone. *Technology and Disability, 20*(3), 225-239.

Nocera, J. A., Dunckley, L., & Sharp, H. (2007). An Approach to the Evaluation of Usefulness as a Social Construct Using Technological Frames. *International Journal of Human-Computer Interaction, 22*(1-2), 153-172.

Notley, T., & Foth, M. (2007). Extending Australia's digital divide policy: an examination of the value of social inclusion and social capital policy frameworks. *Australian Social Policy, 7*, 87-111.

Oliver, M. (1990). *The Politics of Disablement*. London: Macmillan.

Oliver, M. (1996). Defining Impairment and Disability: Issues at Stake. In C. Barnes & G. Mercer (Eds.), *Exploring the Divide* (pp. 29-54). Leeds: The Disability Press.

Owens, J. (2006). Getting It Right: participatory information research with people with disabilities. *International Journal of Technology, Knowledge and Society, 1*(1), 1-6.

Poore, M. (2011). Digital Literacy: Human Flourishing and Collective Intelligence in a Knowledge Society. *Literacy Learning: The Middle Years, 19*(2), 20-26.

Potts, B. (2005). Disability and employment: considering the importance of social capital. *Journal of Rehabilitation, 71*(3), 20-25.

Power, M. R., & Power, D. (2004). Everyone Here Speaks TXT: Deaf People Using SMS in Australia and the Rest of the World. *Journal of Deaf Studies and Deaf Education, 9*(3), 333-343. doi: 10.1093/deafed/enh042

Power, M. R., Power, D., & Horstmanshof, L. (2007). Deaf People Communicating via SMS, TTY, Relay Service, Fax, and Computers in Australia. *Journal of Deaf Studies and Deaf Education, 12*(1), 80-92. doi: 10.1093/deafed/enl016

Rackensperger, T., Krezman, C., Mcnaughton, D., Williams, M. B., & D'Silva, K. (2005). "When I First Got It, I Wanted to Throw It Off a Cliff": The Challenges and Benefits of Learning AAC Technologies as Described by Adults who use AAC. *Augmentative and Alternative Communication, 21*(3), 165-186. doi: doi:10.1080/07434610500140360

Raghavendra, P., Bornman, J., Granlund, M., & Björck-Åkesson, E. (2007). The World Health Organization's International Classification of Functioning, Disability and Health: implications for clinical and research practice in the field of augmentative and alternative communication. *Augmentative & Alternative Communication, 23*(4), 349-361.

Ratcliff, A., Sutton, B. A., & Lehman, M. (2009). Metrics for Comparing Three Word-Based Software Programs Used for Augmentative and Alternative Communication. *Augmentative & Alternative Communication, 25*(3), 176-186. doi: 10.1080/07434610902995932

Segalman, B. (2006). *History of Speech to Speech*. Sacramento, California, USA

Sengara, R. (2009). Campaigning for communications consumers. *Telecommunications Journal of Australia, 59*(3), 1-5. doi: 10.2104/tja09046

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Simmons, B., Blackmore, T., & Bayliss, P. (2008). Postmodern synergistic knowledge creation: extending the boundaries of disability studies. *Disability & Society, 23*(7), 733-745.

Simpson, J. (2009). Inclusive Information and Communication Technologies for People with Disabilities. *Disability Studies Quarterly, 29*(1).

Simpson, J. (2011). Speech Communications Assistance by Telephone (SCT). FCC Filing. WC Docket No. 03-123 Retrieved 1 November 2011, from http://fjallfoss.fcc.gov/ecfs/comment/view?id=6016846585

Stone, E., & Priestley, M. (1996). Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers. *The British Journal of Sociology, 47*(4), 699-716.

Swedish Post and Telecom Agency. (2011). Disability Services Retrieved 28 September, 2011, from http://www.pts.se/en-gb/People-with-disabilities/Services/

Telecommunications (Consumer Protection and Service Standards) Act. (1999). *Telecommunications (Consumer Protection and Service Standards) Act*. Retrieved from http://www.comlaw.gov.au/Details/C2009C00019.

Thomas, C. (2002). Disability Theory: Key Ideas, Issues and Thinkers. In C. Barnes, M. Oliver & L. Barton (Eds.), *Disability studies today* (Vol. Illustrated, pp. 38-54): Wiley-Blackwell.

Tilley, C. M., Hills, A. P., Bruce, C. S., & Meyers, N. (2002). Rehabilitation in practice. Communication, information and well-being for Australians with physical disabilities. *Disability & Rehabilitation, 24*(9), 503-510.

United Nations. (2010). Convention on the Rights of Persons with Disabilities Retrieved 14 May, 2010, from http://www.un.org/disabilities/default.asp?id=259

Van Balkom, H., & Verhoeven, L. (2010). Literacy Learning in Users of AAC: A Neurocognitive Perspective. *Augmentative and Alternative Communication, 26*(3), 149-157. doi: 10.3109/07434618.2010.505610

Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). After High School: A First Look at the Postschool Experiences of Youth with Disabilities. A Report from the National Longitudinal Transition Study-2 (NLTS2). Menlo Park, CA.: SRI International.

Walmsley, J. (2001). Normalisation, Emancipatory Research and Inclusive Research in Learning Disability. *Disability & Society, 16*(2), 187-205. doi: 10.1080/09687590120035807

Webb, J., Schirato, T., & Danaher, G. (2002). *Understanding Bourdieu*. Crows Nest, NSW: Allen & Unwin.

Wilkinson, K. M., & Hennig, S. (2007). The state of research and practice in augmentative and alternative communication for children with developmental/intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(1), 58-69. doi: 10.1002/mrdd.20133

Wood, D. (2010). Communicating in virtual worlds through a Web 2.0 application. *Telecommunications Journal of Australia, 60*(2), 1-16. doi: 10.2104/tja10019

Zarb, G. (1992). On the Road to Damascus: First Steps towards Changing the Relations of Disability Research Production. *Disability & Society, 7*(2), 125-138. doi: 10.1080/02674649266780161