Lived experiences of people with complex communication needs: Romantic and sexual relationships

by

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Dedication

For the memory of Chris Wilson ‘Mum’

and for the Eglinton family.

Candidate's Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Candidate's Name: Darryl James Sellwood

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Date: 20th March 2019

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This is to certify that the research carried out for the doctoral thesis, "Lived experiences of people with complex communication needs: Romantic and sexual relationships", was completed by Darryl James Sellwood in the Disability and Community Inclusion Unit, Flinders University, Adelaide Australia. The thesis material has not been used in part or in full for any other qualification, and I confirm that the candidate has pursued this course of study in accordance with the requirements of Flinders University regulations.

Supervisor's Name: Associate Professor Parimala Raghavendra, Ph.D.

Supervisor's Signature:

Date: 22th March 2019

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This is to certify that the research carried out in the doctoral thesis, “Lived experiences of people with complex communication needs: Romantic and sexual relationships”, in the Disability and Community Inclusion Unit, Flinders University, Adelaide Australia is the original work of the candidate, except as indicated by appropriate attribution in the text and/or in the acknowledgements; that the text excluding appendices/annexes, does not exceed 100,000 words; all ethical requirements applicable to the study have been complied with as required by Flinders University of South Australia, other organisations and/or committees which had a particular association with this study, and relevant legislation.

Ethical authorisation code: 7029 Flinders University Human Ethics Committee

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Date:

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The late Chris Wilson. I bought you a clown doll, that I never got to give you before cancer got you. The other day, someone must have knocked the doll, kept in pride of place in my kitchen, and after decades of silence it played a few notes of *Send in the Clowns*. I was reminded of your support of all my endeavours in my teens. Thank you ‘Mum.’

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Publications and presentations relating to this study

Journal Publication

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Abstract

Background: Human beings are social by nature. People with and without disabilities pursue romantic and sexual relationships for wellbeing and to meet their social, emotional, physical and sexual desires and needs. A systematic literature review was conducted investigating the perceived barriers and facilitators experienced by people with congenital physical and communication disabilities in socializing, sharing intimacy and expressing sexuality. It revealed that little was known of such experiences by people with congenital physical and communication disabilities.

People with complex communication needs can use Augmentative and Alternative Communication (AAC) systems and strategies to assist in communicating and expressing themselves. The AAC field supports people with complex communication needs to live their lives to their full potential through clinical practice grounded in evidence-based intervention. Based in large part on the United Nations Convention on the Rights of Persons with Disabilities, the field focuses on building communicative competency, education, living skills, social networks and employment. However, it was evident that the rights embedded in the Convention were not completely addressed because of the absence of information on, and understanding of, the lived experiences of people with complex communication needs in developing romantic and sexual relationships. This lack of evidence makes it challenging to provide adequate services and policies to assist them in forming adult relationships. The aims of this research were to investigate the lived experiences of people with complex communication needs in developing romantic or sexual relationships, and to identify barriers and facilitators they encounter in these pursuits.

Method: This research deliberately sought lived experiences in an area that is seldom discussed openly, employing a critical hermeneutics approach and Feminist Standpoint

Theory. Nine participants who had complex communication needs were interviewed regarding their lived experiences in developing romantic and sexual relationships.

Results: All participants were 21 or older, had a physical and communication disability since childhood, and used AAC. The findings revealed that most had enjoyable sex lives. Most participants identified as heterosexual and only two were in ongoing relationships. However, compared to the general population, the participants encountered additional barriers and facilitators. Five significant factors appeared in many of their experiences: attitudes of others, assistance of support workers, communication in intimate moments, sex and disability education, and the attitudes of the participants themselves. Assistance of family, friends, support workers and professionals acted as a facilitator, but ableist attitudes were also prevalent among them, adding to the barriers. Support workers were facilitators for participants to develop relationships, however, employment policies often hindered the provision of assistance with sexual activity. AAC devices supported social interaction, yet they were difficult to use in more intimate situations and their slowness could have prevented people from meeting potential partners. Participants also pointed to the lack of relationship and sex education received in their schooling as a significant barrier. Despite the relentless ableism that the participants encountered, their resilience and determination were their most influential facilitators, and they rarely focused on their disabilities as inhibitors.

Conclusion: The lived experiences of the participants provided a unique insight into their audacity and resilience in developing romantic and sexual relationships. Their experiences bring attention to the need for changes in policies, practice and research to further support people with complex communication needs in their quest to develop intimate relationships.

Prologue

Sitting in a bar in San Francisco, the home city of the Independent Living movement and the LBGTIQ movement, the feet on the stool in front of me invited me to massage them. As I proceeded, my relationship with the woman, whom I had met just moments before while dancing in the piano bar, seemed to deepen beyond the friendship stage.

Part way through my PhD candidature, I attended a conference in Canada where I presented preliminary findings of my research. In planning the trip, I decided to take the opportunity to stop over in San Francisco, to explore the city where so many influential social movements began. As I have a communication and physical disability, I use an electric wheelchair and an Alternative and Augmentative Communication (AAC) device. When I travel, I usually take a support worker with me to assist me with personal care. If my speech is too difficult to understand and my AAC too slow to use, the support worker also helps with communication.

One evening my support worker, Anton, and I decided to head back to our hotel room. We had spent a full day out doing the usual tourist activities and we had just enjoyed dinner at a jazz club. We were ready for bed. As usual, I was driving my electric wheelchair ahead of Anton, occasionally stopping to allow him to catch up with me. I was no more than 15 minutes from our hotel when I heard a familiar Australian song from my childhood being sung by a group of people in a bar. The song was *Living Next Door to Alice,* which was first a hit in 1972 by the Australian band *New World Trio* and became a worldwide hit in 1976 for the British band, *Smokie*. I had to go in. With a sense of autonomy, self-determination and freedom, I indicated to Anton, when he caught up, to open the door so I could enter. In the front of the bar there was a guy playing keyboards and singing at a large table with approximately 20 people. Anton soon realised that we were going to be there for a while and offered to get some drinks for us. A group of Australians on the other side of the table were singing along, with some locals and other nationalities joining in.

People like me, who have communication and physical disabilities, can rarely be spontaneous. Most of the time we must plan, due to the support and accessibility required, to do even the most routine daily tasks. One of the main reasons I like to take Anton away on these trips, is that we work well together. We tend to go with the flow. We roughly plan together what we want to do, however, if things get in the way due to my being in a wheelchair, we are both happy to detour from the planned activity. Anton and I did have a plan that night. We had agreed that we would finish our meal and head back to the hotel to go through the nightly routine needed before going to bed. Hearing the patrons of the piano bar singing along was too good an opportunity to drive past, and I found myself being able to spontaneously decide to extend my evening by following the singing into a bar full of music.

A couple of women near me were dancing. I decided to join in. Anton and I have been friends for years and had been out socially on numerous occasions. He assists me in professional situations, including with my communication. We both enjoy meeting new people and initiating conversations. I find it especially easy when I have someone like Anton with me. A conversation started with the two women we were dancing with. I used a mixture of communication techniques in the conversation. Being in a loud environment I mostly used my AAC device to communicate, occasionally using my voice, shouting a word or two to Anton for him to expand on in the conversation. Even though it was only a few words, mostly he knew what I was trying to say and which way I wanted to contribute to the conversation.

While dancing, I started a conversation with one of the women. Her name was Joanne and she and her friend Meredith were from New Zealand. They were in San Francisco to compete in a sporting event. I mostly used my AAC to talk with her, however, sometimes gestures were all we needed to keep the conversation rolling. As Joanne and I kept dancing, Anton and Meredith sat nearby and talked. Anton knew to leave me alone but to be close by in case I needed help. After dancing for a while, we went to the bar and Joanne offered to buy me a drink. The barman asked me what I wanted. Using my device and gestures to Anton, I asked the barman if they had a vodka called *Chopin*, which I discovered a few nights before and that had become my favourite drink. The barman instantly indicated to the group that I was a man who knows his vodka. In serving me the vodka, like a good barman, he briefly engaged in conversation. He gave me one of those nods that suggested he was impressed with my success. It felt good to be seen in this way.

While we were dancing again, another guy who had consumed much more alcohol than us tried to join in with us. I felt terrible for doing so, but I kept using my wheelchair to block him out, assuming my new friends did not really want that kind of attention. Soon after we were back at the bar. Joanne was relaxing, sitting on a stool with her shoes off from dancing and occasionally helping me take a sip of my drink. She decided to put one of her legs across my lap and rest her foot on a stool close to my wheelchair.

When I saw Joanne's bare foot where I could reach it, I started to massage it, and this seemed to give her great pleasure. My thoughts went to another doctoral research project about men with cerebral palsy seeking intimacy (Shuttleworth, 2000a), as offering foot rubs was one of the research's dating recommendations. As a doctoral candidate with complex communication needs, having a physical and communication disability, it was not my intention to turn this moment into research, yet I remember thinking I now had evidence that supported Shuttleworth's findings.

Massaging Joanne's foot, it felt as if our relationship was advancing to a new level. Enjoying the moment, I realised I had decisions to make. Some of these decisions would be what most able-bodied people would have to make, such as whether to pursue the relationship or politely end it. But I had additional decisions to contend with which were directly influenced by having a disability. If I attempted to take it the way most men would like to, where would it go? Would her hotel room be accessible? If we went to the room Anton and I shared, what would Anton do for the night? Would Joanne understand my speech if we went to bed together? How would I transfer from my wheelchair onto the bed? What would happen if I needed assistance that Joanne did not feel comfortable with?

My thoughts then went to the reason why my new friends, Joanne and Meredith, were there. They were competing in a sporting event in a few days, and were planning a rest day before the event. Furthermore, I knew that Anton was already tired, and I did not want him to become over-tired as I realised that that would put added pressure on our working relationship. So, I decided to retire as gracefully as I could by indicating to Anton to say that we needed to go. After exchanging Facebook details and numbers and saying our goodbyes we left the now half-empty bar to go to our respective hotels.

The next day I thought I would try to re-connect with Joanne. Although I knew that it was probably a moment that just happened, and one that I should just enjoy for whatever it was, part of me was hoping it would develop into more. Yet the relationship ended up just being Facebook friends with someone that I used to know.

The names have been changed to protect people’s identities, but all this brought into sharp focus the kind of issues that this doctoral research has started to unveil; issues encountered by people who have complex communication needs in developing romantic and sexual relationships. In my University studies I have always been intrigued by psychology and sociology theories. In my Honours Degree, I encountered several theorists who sparked my interest in the range of human sexuality and in doing research that could help people live satisfying lives. Various documentaries had opened my eyes to the sexual needs of people with disabilities and challenged my beliefs, especially the Australian documentary, *Scarlet Road,* featuring sex worker Rachel Wotton (Fiske & Scott, 2011).

As a person with strong Christian beliefs, I struggled with the whole area of sexuality for many years. More recently, I have found myself in intimate relationships and discovered that even as a capable and educated person, I needed information. This combination of my thoughts, experiences and professional knowledge has led me to this research. It is my hope that my research will not only contribute to the development of AAC practices and research, but also assist lovers who have complex communication needs and use AAC to develop successful romantic and sexual relationships.

1 Introduction

1.1 Background

Human beings are social beings who, by nature, need to develop different types of relationships to meet their personal needs, to survive, and to enhance their wellbeing. Romantic and sexual relationships can meet needs of belonging, intimacy, companionship, physical touch, security and sexual activity (Erber & Erber, 2017). Romance has enjoyed the attention of poets, musicians, playwrights and scholars since the time of the ancient Greeks (Lamy, 2016), and even neuroscientists in recent times (Cacioppo & Cacioppo, 2016). It was William Shakespeare (1895) who wrote in *A Midsummer Night Dream*, "Love looks not with the eyes, but with the mind, And therefore is winged Cupid painted blind" (W. Shakespeare & Bates, 1895, Act I, Scene I).

According to Lamy (2016), a romantic relationship starts when one person is attracted to another. The relationship between them transcends the platonic. Their attention is drawn to admired characteristics; lesser desired personal features fade out of awareness. Becoming emotionally dependent on each other, the couple change their daily life to accommodate development of the romantic relationship.

People pursue traditional intimate relationships for social and emotional support, to meet physical needs for touch and sexual gratification and to boost self-esteem and self-confidence (Jonason & Balzarini, 2016). Other relationships can exist between friends who occasionally have sex together without romantic ties. These "friends with benefits" relationships are primarily for physical intimacy and sexual gratification (Jonason & Balzarini, 2016). This implies a friendship which has a degree of intimacy, but research has reported a recent trend of an increase in "hook-up" type relationships, that tend to be transitory, non-committal, sexual relationships between individuals—often strangers or acquaintances (Jovanovic & Williams, 2018). With the rise of electronic communications in mainstream society, online dating has become increasingly popular for meeting potential romantic or sexual partners (Aumer, 2016).

The predominant focus of the literature is on the experiences of able-bodied people in needing and forming intimate relationships. However, the literature concerning the experiences of people with disabilities developing these types of relationships is limited and constitutes a significant lack of available evidence.

1.2 Disability and Sexuality

It was estimated in 2011 that there were over one billion people, approximately 15% of the world's population, living with at least one disability (United Nations, 2018). The 2015 Australian Census data reported the Australian population as 23.9 million, of whom 4.3 million had disabilities—1.4 million being profound or severe in nature (Australian Bureau of Statistics, 2016a). Half of the population with disabilities required some sort of assistive technology support and approximately 60% required assistance with daily living tasks. Compared to the able-bodied population, where 83% were employed, only 53% of people with disabilities were in paid work (Australian Bureau of Statistics, 2016c). Unfortunately, there is no data available on the social relationships of people with disabilities.

People with disabilities are more likely to experience difficulties with sexual or intimate activities (Valvano, West, Wilson, Macapagal, Penwell-Waines, Waller & Stepleman, 2014) and are often subjected to the misconception that they are asexual (Milligan & Neufeldt, 2001). They are frequently treated as children requiring protection from sexual knowledge and experience (Gammino, Faccio, & Cipolletta, 2016). The broader population is generally oblivious to the sexual activities of people with disabilities (Shildrick, 2009). Emerging adults are frequently denied access to sex education in schools and to sexual health providers and are less likely to be encouraged to participate in romantic relationships and exploration of their sexuality (Shildrick, 2009). Despite these obstacles, people with disabilities experience similar emotional, physical and sexual feelings, desires and needs to the general population (East & Orchard, 2013), and many "lead healthy, exciting, and fulfilled sexual lives and partake in a range of diverse forms of sexual expression" (Campbell, 2017, p. 3).

People with congenital disabilities, who have grown up living with a disability, require different support in exploring their sexuality and developing intimate relationships from the support required by adults who have acquired their disability later in life (Wiegerink, Roebroeck, Bender, Stam, & Cohen-Kettenis, 2011). It has been argued that people with acquired disabilities require more of a rehabilitation approach that assists them to adapt to new life circumstances and changes in their sexuality. Those with congenital disabilities, on the other hand, have different lived experiences and support requirements and, therefore, require a developmental approach (Wiegerink et al., 2011). There is very little research into the lived experiences of people with congenital disabilities in developing romantic or intimate relationships (Czapla & Otrębski, 2018; Sellwood, Raghavendra, & Jewell, 2017; Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013; Wiegerink, 2010).

1.3 People with complex communication needs

People with complex communication needs can have a physical or intellectual disability as well as limited functional speech for everyday communication (Beukelman & Mirenda, 2013; Collier, Mcghie-Richmond, & Self, 2010). In Australia, in 2015, there were 1.2 million people with communication disabilities (Australian Bureau of Statistics, 2016b). This group is rarely represented in the broader disability discourse (Iacono, 2014).

The ability to use speech is vital to most daily tasks including socialising, employment, shopping, seeking medical advice and developing friendships. Beukelman and Mirenda (2013) state that people with complex communication needs are "unable to meet their daily communication needs through natural speech. Yet, effective communication is essential for learning and development, personal care, social engagement, education, and employment" (p. 3).

1.4 Augmentative and Alternative Communication (AAC)

People with complex communication needs can use Augmentative and Alternative Communication (AAC) strategies and systems to assist in expressing themselves and to communicate with others beyond their immediate circle of acquaintance (Beukelman & Mirenda, 2013). The AAC field aims to address the unmet needs of people with complex communication needs (Beukelman & Mirenda, 2013).

Modern AAC has its roots in the social movements of the 1950s and 60s which raised awareness about the need to integrate people with disabilities into mainstream society (Griffiths, Bloch, Price, & Clarke, 2019). The Candidacy model described by Beukelman and Mirenda (2013) was originally used for assessing people who could benefit from an AAC system. The person had to demonstrate that they had the skills to use the AAC system before they could be considered for the system. More recently, assessment is based on the communication needs of the person with the understanding that people can learn by using the proposed AAC solutions (Brady et al., 2016).

According to Griffiths et al. (2019), AAC strategies can be traced back four hundred years to people with no speech communicating using rudimentary signs. For those who had good literacy skills, writing with pen and paper was used to support communication. In the 1920s, communication boards, which enabled users to point to letters and phrases, began to be printed commercially.

AAC strategies can be *unaided, aided* or *multimodal*. Unaided strategies include gestures, speech, vocalisations, eye pointing and signing without the use of any other aids or props. Aided solutions refer to objects used for communication such as pointing boards, communication books and even simple paper and pen. High-tech solutions like AAC devices, electronic devices designed for communication, often with speech output, are also classified as aided solutions. Multimodal refers to communication strategies which use more than one of these strategies, for example where a person uses gestures or signing as well as using an electronic communication device (Beukelman & Mirenda, 2013). The greater the disability, the greater the complexity of the communication strategies/system needed and the more difficult it is to implement (Iacono, 2014).

With the rise of computer technology and the invention of the personal computer in the 1960s, AAC solutions also began to be developed using these machines. These high-tech solutions have advanced along with the development of mainstream technologies. Since the 1960s, companies such as Possum[1] and Prentke Romich[2] have been developing and manufacturing dedicated AAC devices for the specific purpose of supporting people with communication difficulties to converse with others. There is currently a debate over whether AAC devices need to be dedicated devices or whether mainstream technologies, such as electronic tablets, can be used (Griffiths et al., 2019). However, that debate is out of the scope of this thesis.

Currently, AAC systems utilise different symbol systems to convey meaning of concepts and messages (Beukelman & Mirenda, 2013). Orthography-based systems, utilising written symbols, are useful for people with good literacy but can be difficult for those who have poor literacy development. Numerous graphic symbol-based systems have been used to assist people who lack literacy skills or have an intellectual disability. Along with the range of

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[1] Possum Ltd: 8 Farmbrough Close, Stocklake Park Industrial Estate, Aylesbury, Buckinghamshire, HP20 1DQ, United Kingdom.
Website: www.possum.co.uk

[2] Prentke Romich Company (PRC): World Headquarters, 1022 Heyl Road, Wooster, OH 44691 USA
Website: www.prentrom.com

symbol systems used, the methods people use to access AAC systems have also advanced as mainstream technologies have developed. Access methods include using single switches to select items on a computer screen, using touch screen tablets and using a finger or a pointer to point to letters, words, phrases or symbols. The recent introduction of eye gaze technology has opened up high tech devices to people who have otherwise not had access to AAC systems (Griffiths et al., 2019).

Although there are communication strategies and technology to assist people with complex communication needs to participate in their communities, it is not as simple as giving a person a touch screen tablet for them to type what they want to say because their physical and cognitive abilities also need to be taken into account (Beukelman & Mirenda, 2013). Stephen Hawking, the renowned theoretical physicist, had complex communication needs as a result of motor neurone disease. Despite his high intelligence, his physical limitations meant that he could only use a single button to operate his communication device (Hemsley, 2018).

People who rely on using AAC strategies frequently encounter difficulty in communicating with others. Because of their communication challenges, some presume that their intelligence is also impaired, so they speak more loudly and slowly, assuming that this will increase comprehension. Some may find that others lack the patience to converse with them, as using their own dysarthric speech or AAC devices can be slow (Iacono, 2014). Although literacy and the speed of generating messages within social settings remain issues, AAC has been shown to improve the social participation of people with complex communication needs (Balandin, 2011).

Environmental factors can also make it difficult for people with complex communication needs to socialise and meet people. Traditionally people tend to meet potential partners while socialising in public places such as hotels, clubs and churches (Ballin

& Balandin, 2007). These public venues typically present physical access barriers, making it difficult for people with physical disabilities to enter them (Iacono, 2014). Public places are often noisy environments which make communication by speech difficult (Ballin & Balandin, 2007). However, social participation is a critical mechanism for developing romantic relationships.

1.5 Romantic and Sexual Relationships among people with complex communication needs

A systematic review of the literature was undertaken in relation to the perceived barriers and facilitators experienced to socializing, sharing intimacy and expressing sexuality of people with communication and physical disabilities, according to them and their supporters (e.g., friends, family, partners and professionals) (Sellwood et al., 2017). The review found that although people with communication and physical disabilities do develop romantic and sexual relationships, little is known of their lived experiences and the barriers and facilitators they encounter.

Jeeja Ghosh, a disability activist from India who has cerebral palsy and speech difficulties, recently gave a TEDx talk on the multi-layered oppression experienced by people with disabilities, especially in relation to sexuality (TEDx, 2019). Educated in Social Work, Ghosh drew on her lived experience growing up as a woman with cerebral palsy and frequently having her sexuality denied. She argued that people with physical and communication disabilities are immersed in oppression from society which they internalise and thus impose limitations on their potential.

> *Society imposed restrictions on any kind of sexual expression by persons with disabilities. I witnessed a similar reaction during my college years.*

> *Certain situations and incidents made me painfully conscious of my disability and made me feel like an outcast.*

Growing up with cerebral palsy and attending mainstream schools, she questioned the concept of integration as she had a sense of “not belonging to this world.” She had the usual feelings and urges of wanting intimacy, falling in love and experiencing crushes. Although she was a part of a social group, had supportive college friends, she remained socially isolated. Witnessing her able-bodied peers dating, she felt there was an unseen division between her and them when it came to her sexuality. This was a division which she felt her peers imposed, seeing her as a “disabled girl” and not a sexual being. She spoke of her sexuality or desires being “opaque, a thing to be skilfully ignored,” and a feeling of never fitting into the social group of her able-bodied peers.

These perceptions were reinforced by comments from her peers such as, “If you were not like that (disabled), you would be sexually attractive,” which made her question her womanhood, denied her the right to show romantic feelings. She felt unworthy of any attention from others beyond the usual social exchanges, especially if they were male. She even felt that she could not do academically better than others for fear of being ostracised. As Ghosh asserted, this is a common experience for people with disabilities and many can become depressed.

1.6 Theoretical overview

The experiences which Ghosh described emphasise the need for research such as this into the lived experiences of people with complex communication needs. In order to conduct this research, a theoretical framework was constructed to structure the data collection and analysis. The framework provided a lens to an in-depth understanding into the experiences of the participants. The developed framework draws on the concept of ableism (Campbell, 2017), critical hermeneutics (Lopez & Willis, 2004), Feminist Standpoint Theory (Haraway,

1988) and the International Classification of Functioning, Disability and Health (ICF) framework (World Health Organization, 2013). A brief description of the theoretical framework is provided below with a detailed discussion presented in Chapter 4.

1.6.1 Concept of Ableism

Ableism is a type of discrimination which gives preference to able-bodied individuals and views them as normal, degrades those with a disability, resulting in prejudice toward the latter. The prejudicial attitudes be can individual, societal, and institutional (Levi, 2006). Commonly, people with ableist attitudes “view disability as an unfortunate, individual, biomedical problem that requires treatment or rehabilitation” (Campbell, 2017, p.1). Ableism is shaped by practices and dominant attitudes in society that devalue and limit the potential of people with disabilities (Levi, 2006).

1.6.2 Critical hermeneutics

A critical hermeneutics approach was utilised in this research to explore the participants’ lived experiences (Creswell, 2012). This is an extension of the interpretive tradition in phenomenology which attempts to provide a deeper understanding and knowledge of people on the edge of society (Lopez & Willis, 2004). It allows the researcher to draw on prior knowledge and to incorporate theoretical frameworks into the analysis of the phenomenon. There is an assumption that the researcher is external to the cohort being studied. However, for this project, the researcher is a member of the cohort being studied and has knowledge as a member of that cohort. Feminist Standpoint Theory was employed for its acknowledgement of this knowledge.

1.6.3 Feminist Standpoint Theory

Feminist Standpoint Theory is set apart from conventional philosophy by its aim to obtain understanding and knowledge of a phenomenon, to investigate ways to overcome injustice and social power inequities in order to generate positive social change (Daukas, 2017). It acknowledges the position of researcher as being the *insider knower* in relation to the phenomenon being studied. This concept, called *situated knowledge* (Haraway, 1988), can influence the understanding and knowledge of the social relationships. Contrary to traditional epistemology, where the outsider researcher is deemed a *privileged knower*, Feminist Standpoint Theory gives privilege to the situated knower, acknowledging their insider knowledge of the cohort. The situated knowledge of the insider researcher enables the researcher to have access to knowledge that may not be available to the outsider researcher (Haraway, 1988).

1.7 First person language

It is a characteristic of Feminist Standpoint Theory that first person language is used to indicate the researcher's situated knowledge (see Haraway, 1988; Harding, 2004). Therefore, to ensure that the knowledge generated from my standpoint is clearly indicated, first person language has been used in chapters: Introduction, Theoretical Framework, Discussion and Conclusion. The remaining chapters, which mostly report information, have been written in third person. To assist the reader to understand the researcher's interpretation of the findings, it is important for the researcher to state their standpoint and how they have obtained their situated knowledge.

1.8 Personal standpoint

As the researcher, my standpoint is as a person with a physical disability and complex communication needs. Having had cerebral palsy and dysarthric speech since birth, I have had numerous assistive technologies such as walking frames, wheelchairs and a variety of communication devices. Although these have helped to a degree with my communication, they were often difficult and slow for me to use effectively. It was not until my mid-thirties that I found a device that came close to being effective in allowing me to carry on a conversation easily, thanks to improvements in the technology. While assistive technology can improve one's ability, it must be recognised that the level of improvement is incremental. While a walking frame enabled me to walk, I could not walk as fast as my peers. And although my wheelchair can travel much faster, I cannot climb stairs. Similarly, while a communication device helps me communicate, I often prefer using my own voice with people who know me as, in most cases, it tends to be quicker.

However, my lived experience also includes being involved, both as a participant, in so many academic research projects that I have lost count, and as a researcher. My earliest memory of being a research participant was spending two hours in a room with a nervous undergraduate physiotherapist who was trying to assess me, so that when we met again a week later they could report their findings to their supervisor. They would try to teach me skills such as how to balance independently or to roll over. For my time I received 20 cents which, at the time, bought a bag of lollies or a can of coke.

I have been involved in research projects and assessments in a variety of areas: accommodation, normalisation, recreation, assistive technology, telecommunications, independent living, shopping independently, diet and psychological profiles. I have been interviewed for seemingly endless high school projects on disability. I participated over the phone in research about social security benefits, which ended in failure as they did not have the patience to listen for my responses. Some of the projects I thought were useful. There have been some I declined, because I thought that it might be difficult to convey the wealth of knowledge that I had, due to the projects' time constraints and my complex communication needs.

I have a background in computer technology. My first degree was in Computer and Information Technology. Following this, I completed a Bachelor of Arts (Honours), researching how people with complex communication needs use telecommunications. Undertaking the research gave me a good introduction to researching in general, and more specifically to undertaking research with people with severe communication disabilities. I dived into various theories, such as queer theory, which led me to contemplate how these theories relate to people with complex communication needs.

1.9 Terminology: identity-first or person-first

The other noteworthy feature of the language used within this thesis is the interchangeable use of person-first and identity-first language when referring to people with disabilities. The use of person-first language is strongly recommended within AAC literature, so the field prescribes the use of “people with disabilities” rather than “disabled people” or “people using AAC devices” rather than “AAC users” (International Society of Augmentative and Alternative Communication, 2010). This is an attempt to put the focus on the person instead of on the disability or on the assistive technology. In surveying the literature, I became increasing uncomfortable with the person-first form and noticed a pattern emerging. It seemed that in broader disability literature researchers who used the people-first language form tended not to have a disability. Although it is out of respect for people with disabilities that the person-first form is used, people with disabilities often argue that it can do the opposite, by playing down their disability. It can suggest that the disability is the problem and, in effect, is a denial of a part of their person (Liebowitz, 2015). For those who consider their disability is part of their identity, or links them to a cultural group, and thus have a sense of pride, identity-first language is preferred (Campbell, 2017; Clare, 2001). Researchers with disabilities tend to use both forms with a statement that acknowledges this semantic debate (Campbell, 2017). As a disabled researcher, I too have adopted this approach of interchanging the use of person-first and identity-first language.

1.10 Significance

This exploratory research contributes a unique insight into the romantic and sexual lives of people with complex communication needs. It focuses on the experiences of people with complex communication needs in developing romantic and sexual relationships and aims to provide insights into their lives. The Disability and Sexuality field has enjoyed growth within the last few decades (Campbell, 2017). However, the voices of people with communication and physical disabilities are rarely included in this conversation (Sellwood et al., 2017).

This research has a focus on a group of people who have had a physical disability from childhood. By doing so, it has empowered the participants to contribute to society's understanding (Lopez & Willis, 2004). This could be useful in improving the types of services that can support them in their pursuit of successful romantic or sexual relationships, which are central to the wellbeing of all human beings (World Association for Sexual Health, 2014). Utilising critical hermeneutic and Feminist Standpoint Theory enabled me, the researcher, to bring to this research my prior knowledge of the cohort and my own lived experiences as a person with complex communication needs. This has enhanced the relevance of questions asked in interviews, facilitating a unique insight into analysis and understanding of data. The distinguishing contribution made to research evidence is the perspective derived from the voices of those who are not often heard concerning a very personal and taboo topic. It begins a much-needed conversation within the field of AAC and the broader Disability field.

1.11 Chapter synopsis

This dissertation has eight chapters and an epilogue, each focusing on different aspects of the research. **Chapter 1** introduces this study by presenting the background to the study, the problem statement, the significance of the study, the research questions and the research objectives. The chapter concludes with a synopsis of the chapters.

Chapter 2 presents a green copy of a systematic review published in the Sexuality and Disability Journal, called *Sexuality and Intimacy for People with Congenital Physical* *and Communication Disabilities: Barriers and Facilitators: A Systematic Review* (Sellwood et al., 2017) published by me and two of my supervisors during my candidature. It states the methodology used, presents the results of the systematic literature search and the themes which emerged from analysis of fifteen identified papers. The chapter discusses each theme and concludes that little is known of the lived experience of people with complex communication needs in developing romantic and sexual relationships and calls for further research.

In response to the Systematic Review, **Chapter 3** contains the literature review which commences with a description of the key terms, followed by a critical review of the literature findings concerning romantic and sexual relationships more broadly. To provide contextual background, I discuss the disability movement and the theoretical models that have been used to understand disability. This includes investigating the power of the State over the private lives of people with disabilities. An exploration of the literature which focused on both disability and sexuality was undertaken, followed by a focus on the communication and participation challenges for people with complex communication needs who use AAC—with a specific focus on social relationships. The chapter concludes with the research questions, rationale and the aims of this study.

Chapter 4 outlines the theoretical framework utilised to collect and analyse the interview data in order to understand the lived experiences of people with complex communication needs. It presents the features of the framework: critical hermeneutics, Feminist Standpoint Theory, the International Classification of Functioning, Disability and Health, and the concept of ableism.

Building on the theoretical framework, **Chapter 5** discusses the methodology used in the current study. It also presents the rationale for the qualitative approach utilised, then discusses the methods, including the data collection and analysis processes.

Chapter 6 presents the results, commencing with a brief description of the participants, ensuring their anonymity, followed by an analysis of the interviews. Five themes describing the lived experiences of the participants are presented, followed by three themes identified as relating to the barriers and facilitators encountered in developing relationships.

The discussion, **Chapter 7**, explores the characteristics of the participants and their experiences to give context to the findings and discusses six over-arching themes that were drawn from the results. New understanding and knowledge are presented and examined through these six factors and, based on these, suggest potential implications for policies, practice and future research.

Chapter 8 draws conclusions, highlighting the unique and important contributions of this research.

The **Epilogue** addresses the people with complex communication needs themselves. It discusses key findings which they could find useful, while also offering some social and relationship advice.

2 Sexuality and Intimacy for People with Congenital Physical and Communication Disabilities: Barriers and Facilitators—A Systematic Review

At the commencement of this research, it was decided to conduct a systematic review to ascertain what prior research had been conducted on the topic of sexuality and intimacy within the cohort of people with complex communication needs. As the researcher and his supervisors had prior knowledge that there had been very little research on this topic with this cohort, it was decided to broaden the scope to include people with congenital physical and communication disabilities. This chapter is a pre-published version of the following systematic review:

> Sellwood, D., Raghavendra, P., & Jewell, P. (2017). Sexuality and intimacy for people with congenital physical and communication disabilities: barriers and facilitators: a systematic review. *Sexuality and Disability, 35*(2), 227–244. doi:10.1007/s11195-017-9474-z

The concept of the systematic review was developed in a supervisory meeting. In accordance with the Higher Degrees by Research Policy of Flinders University, the percentage contribution by each author is acknowledged as follows: Sellwood (researcher), 75% of Research Design, 55% of Data Collection and analysis and 70% of Writing and Editing; Raghavendra (primary supervisor), 20% of Research Design, 35% of Data Collection and analysis and 25% of Writing and Editing; Jewell (supervisor), 5% of Research Design, 10% of Data Collection and analysis and 5% of Writing and Editing. The researcher acknowledges the additional contribution made by Raechel Damarell, Senior Liaison Librarian for Medicine, Nursing and Health Sciences of Flinders University for her expertise and time in the development of the search criteria. Additional assistance with editing and formatting was provided by Claire Hutchinson, Research Assistant. Conducting the systematic review proved to be a valuable exercise, reinforcing the need for further research in this emerging field and helping shape the questions for the current research.

2.1 Abstract

Barriers and facilitators affecting the social activities of people with congenital physical and communication disabilities are well documented. However, little is known of their experiences of developing sexual and intimate relationships. This study conducted a systematic review of the literature to address this gap in knowledge. Ten online databases were searched for relevant papers between 1990 and 2014. In addition, hand searches of the *Augmentative and Alternative Communication Journal* and the *Sexuality and Disability Journal* were conducted. Fifteen papers were identified and appraised. The thematic coding approach identified six principal themes. However, the content analysis revealed that the majority of the literature focused on the social needs of people with physical and communication disabilities. Despite evidence that people with disabilities are sexually active, there is little focus on the experiences of people with disabilities developing intimacy and expressing sexuality. The few references to sexuality in the relevant literature focused on protection from abuse, though some researchers called for improved counselling on sexuality and relationships, and improved access to sexual health services. Further research is required to focus on practical and theoretical outcomes to enhance social relationships and sexuality, and to offer lovers who use augmentative and alternative communication (AAC) real advice in their search for intimacy.

2.2 Introduction

Sexuality goes beyond anatomic and physiologic functioning. It includes sexual knowledge, beliefs and values, as well as social gender roles, physical development, body image, social relationships, perceived social value, feelings of physical attractiveness, and the sharing of thoughts and feelings (Butler, 2002).

People with disabilities are sexually active, despite the common misconception that they are asexual and do not participate in sexual activities (J. McCabe & Holmes, 2014). However, people living with disabilities are more likely to experience difficulties with their sexual activities and intimacy (Valvano et al., 2014). People with disabilities often believe they are not sexually attractive due to their disability. Research demonstrates that increased severity of disability is associated with lower sexual esteem and sexual satisfaction, greater sexual depression and less frequent sexual activity (M. McCabe & Taleporos, 2003).

Article 23 of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2013) asserts that people with disabilities have the right to be part of a family and to participate in social relationships. Article 25 states that this group has the right to access healthcare services equal to others, including sexual health services. The Convention also acknowledges that people with disabilities face greater barriers in participating in social relationships than those without disabilities and that there is a need to remove or mitigate barriers to such participation.

Although rehabilitation for adults with an acquired disability focuses on adapting to new life circumstances, including changes to sexuality, people with congenital disabilities have different needs and a developmental approach is considered more suitable for exploring sexuality and intimate relationships (Wiegerink et al., 2011). It is important to allow and encourage children with physical disabilities to gain privacy and develop relationships with their peers; however, it is also acknowledged that they face greater barriers in achieving these outcomes than do their peers without disability (Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013). In the disability sector (Valvano et al., 2014) and in health research (Vaughn, Silver, Murphy, Ashbaugh, & Hoffman, 2015) the focus is often on impairments, daily living skills and employment outcomes, while sexuality and intimacy needs are neglected.

Likewise, Light and McNaughton (2015) argue that for people with limited or no speech who rely on augmentative and alternative communication (AAC) to communicate with others, AAC interventions and research have concentrated on facilitating participation in education, employment and family environments. However, they emphasize the importance of socializing:

> The goals of AAC intervention must be that children and adults […] have the opportunity to live happy and fulfilled lives where they are able to participate fully in education, employment, family, and community life; […] where they have the chance to develop friendships and intimate relationships; and where they have the opportunity to make meaningful contributions to society. (Light & McNaughton, 2015, p. 87)

Despite the achievements in the past 30 years within the field, people with complex communication needs and their communication partners continue to face significant barriers to participation in the broader community and in relationships development (Light & McNaughton, 2015). It is vital for individuals to have communication skills to interact with others and to foster relationships (Collier, McGhie-Richmond, & Self, 2010). The majority of the AAC research relating to sexual activity is concerned with protection from abuse (Light & McNaughton, 2015) and there is little research on supporting communication in building healthy sexual relationships (Collier, McGhie-Richmond, Odette, & Pyne, 2006).

The aim of this study is to review the literature systematically to answer the following question developed through the use of the PESICO—person, environments, stakeholders, intervention, comparison, outcomes (Schlosser, Koul, & Costello, 2006). According to people with congenital physical and communication disabilities and their supporters (e.g., friends, family, partners and professionals), what are the perceived barriers and facilitators experienced to socializing, sharing intimacy and expressing sexuality? Socialization and social participation were included in the research question because they are central to human relationships. The ability and opportunity to interact with friends and new people is vital in forming social relationships and identifying potential intimate partners, and is a key aspect of initiating, developing and maintaining satisfying longer term relationships (Oudekerk, Allen, Hessel, & Molloy, 2015; Simon, Aikins, & Prinstein, 2008).

2.3 Methodology

Increasingly, systematic reviews use a mixed-methods approach, incorporating qualitative and quantitative studies improves the quality of the evidence and assists in decreasing the gap between practice and theory (Harden, 2010; Joanna Briggs Institute, 2014). Thus, the search criteria did not limit the type of methods used.

2.3.1 Inclusion and Exclusion Criteria

The following inclusion criteria were applied: published peer-reviewed studies or doctoral theses from between 1990 and 2014; studies in English; studies where at least one of the participants has a congenital physical disability and a communication disability, or studies where at least one of the participants is a friend, partner, family member or professional providing a service to a person who has a congenital physical disability and a communication disability; any study design that follows research methodology; studies that investigate at least one of the following: social participation, social relationships/friendship, sexual activities, sexuality and/or intimacy. Exclusion criteria were applied to studies where all of the participants were people who had only sensory and/or intellectual disabilities. Grey literature was also excluded.

The studies selected discuss to some degree people's perspectives on at least one of these five listed topics. Social participation refers to socializing with others at work, school, in an educational environment and in leisure activities. Social relationships and friendship refer to interacting with people. Sexual activity refers to any sexual act with others. Sexuality refers to social gender roles, physical development, body image, social relationships and aspirations, and emotional aspects of relationship development, while intimacy refers to developing and maintaining close personal relationships.

2.3.2 Search Strategies

The first author developed the search strategies in consultation with the second author and a senior librarian at Flinders University. The searches were carried out in June 2014. Details of the search strategies are available by contacting the first author. The following electronic databases were searched: Cumulative Index of Nursing and Allied Health Literature (CINAHL), Educational Resources in Education Clearinghouse (ERIC) and Social Abstracts within ProQUEST, Informit, MEDLINE, PsycINFO, PubMed, SCOPUS, and Web of Science. TROVE of The National Library of Australia and The Networked Library of Theses and Dissertations were searched to locate doctoral theses. The limitations of the search engines of these two databases led to the following search strategy: "communicat* AND sexual* AND disab*" using only three key terms. Additional papers that met the above criteria were identified through professional reading and the use of hand searches of the *Augmentative and Alternative Communication Journal* and the *Sexuality and Disability Journal*.

2.3.3 Assessment of Quality of Studies

The eligibility assessment of the studies was performed independently by the first author, initially by assessing the titles, abstracts and keywords. This was followed by an eligibility review of the full text of the remaining studies. The second author independently checked the eligibility of the selected references.

The final selection included qualitative and quantitative studies. These studies were critically appraised to assess quality using the McMaster critical review forms for qualitative (Letts et al., 2007) and quantitative studies (Law et al., 2007). As none of the quantitative studies involved interventions, the intervention section of the Quantitative Appraisal Form was not included to increase the rigour and reliability of this review.

2.3.4 Data Extraction

The first author extracted the data of interest that was related to barriers or facilitators experienced in socializing, sharing intimacy and expressing sexuality. Two principal extraction tables (available on request from the first author) were compiled from the studies included. The first table was a summary of each of the studies containing details of the study purpose, summary of participants, the theoretical framework used and the study design. The second table contained the identified barriers and facilitators together with any relevant conclusions and recommendations for further research.

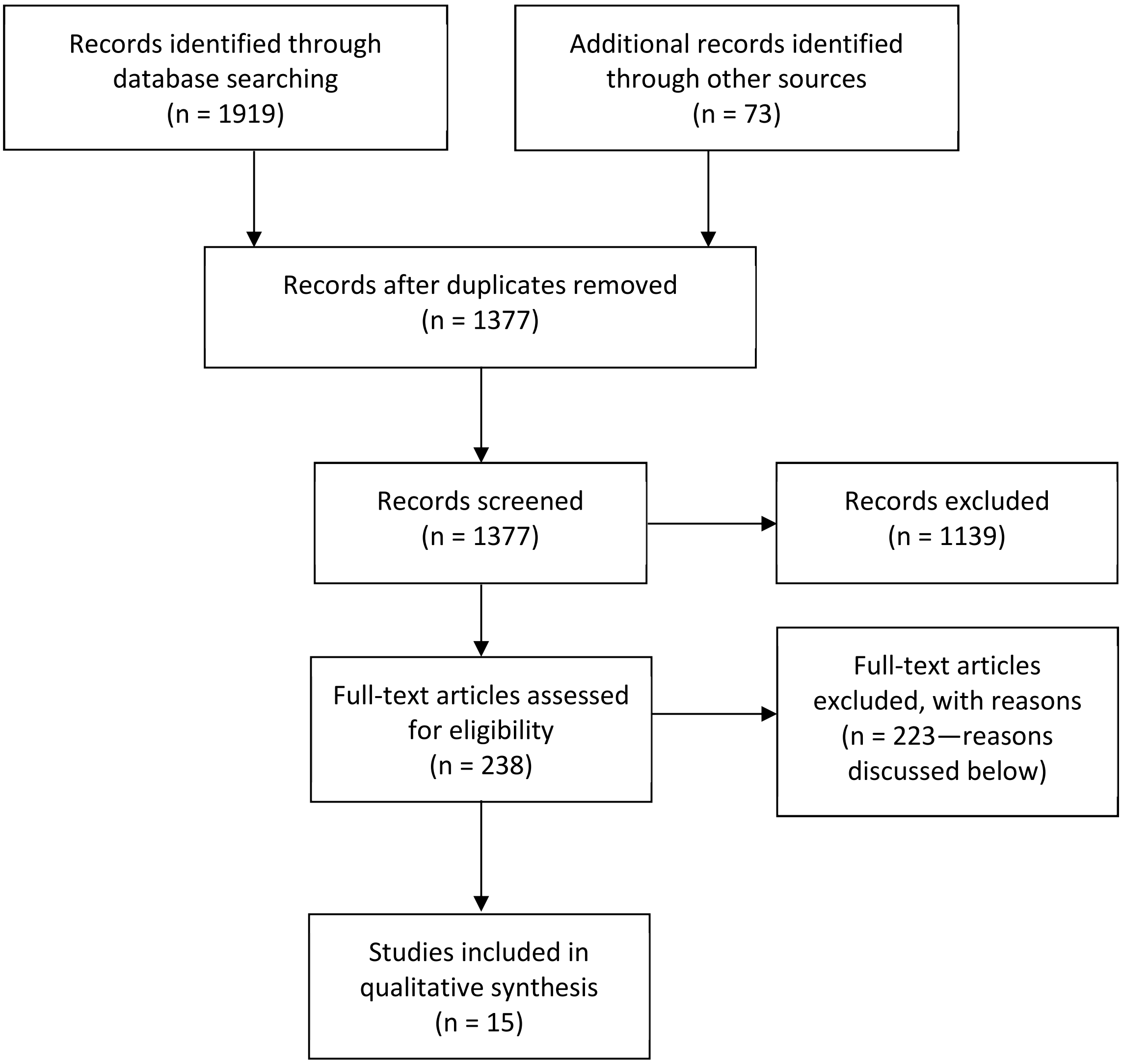
2.3.5 Data Analysis and Synthesis

A data-driven approach was used to identify themes. This method allows researchers the flexibility and freedom to identify and organize themes in a structured manner (Dixon-Woods, Agarwal, Young, Jones, & Sutton, 2004). The synthesis approach was used to identify relationships among data items and develop these into themes. The authors reviewed and refined the identified themes.

2.4 Results

In the identification phase, 1919 papers were collected through the search strategies. An additional 73 papers were included from the first author's professional reading and hand searches. The following number of papers were retrieved from each of the databases: CINAHL: 78, Informit: 43, Medline: 62, ProQUEST: 318, PsychINFO: 208, PubMed: 69, SCOPUS: 540, TROVE: 11 and Web of Science: 590. The PRISMA diagram (Moher, Liberati, Tezlaff, & Altman, 2009) below summarizes the filtering process used to identify the papers that met the criteria mentioned previously stated (see Figure *2.1*). After duplicates were removed, 1377 papers remained. The first author conducted the screening phase, assessing the articles for inclusion based on the relevance of the content of their title and abstract, resulting in the exclusion of 1139 studies.

Figure 2.1 PRISMA 2009 flow diagram



During the eligibility phase, the first author evaluated the full text of the remaining 238 studies and rejected 179 as not meeting the inclusion criteria. The first and second authors independently assessed the remaining 59 papers against those criteria. There was agreement on 73% of the papers and the Cohen's Kappa agreement score was calculated to be 0.44, which represents moderate agreement (Viera & Garrett, 2005). Consensus was reached through discussion on 15 studies, which met all criteria for inclusion in the review. Of the 238 studies, 223 were excluded for the following reasons: 66 studies did not have any participants with communication disabilities or their supporters; 51 studies were not peer reviewed; 50 studies did not have any participants with congenital physical disabilities; 35 studies did not explore social or sexual matters; six studies were not disability focused; six studies did not investigate peoples' perspectives; six studies did not have the full text available; and three studies met the criteria but the presentation of the findings made it difficult to separate relevant and non-relevant data.

The study purposes and participants are summarized in Table *2.1*. This section will present the description and the analysis of the final 15 studies as well as the main themes identified.

Table 2.1: Summary of Studies Meeting the Criteria

No	Citation	Study Purpose	Participants	Study Design
1.	K. Anderson, Balandin, and Clendon (2011)	Research perspectives of peers without disabilities on their existing friendship with students with disabilities and on using AAC	Two friends of each of three students using AAC (n=6)	Thematic narrative with children telling their stories about their friendship
2.	Angelo, Kokoska, and Jones (1996)	Identify needs, priorities, and preferences of parents of adolescents and young adults relying on AAC (with/without physical disabilities) in assessing assistive devices and technology services	Families of children who were registered with the service provider in the United States school year of 1992–1993, and who were aged 13–21 (n=132 parents)	Cross-sectional using postal questionnaires
3.	Ballin and Balandin (2007)	Investigate loneliness of older adults with cerebral palsy and their perception of the effect of their communication and social networks on their loneliness	Seven older adults with cerebral palsy: four men and three women	Phenomenology using in-depth interviews
4.	Collier et al. (2006)	Investigate the risk of sexual abuse for people who use AAC, and methods of reducing this risk	26 people with physical disabilities and who use AAC	Phenomenology using questionnaires, focus groups and individual discussions
5.	Cooper, Balandin, and Trembath (2009)	Investigate the loneliness experiences of young adults who have cerebral palsy and use AAC	Six young adults with cerebral palsy, high support needs and using AAC	Grounded Theory using interviews

No	Citation	Study Purpose	Participants	Study Design
6.	Dattilo et al. (2008)	Investigate perceptions of recreation activities and leisure experiences of adults with cerebral palsy	Eight adults with cerebral palsy and using AAC	Phenomenology using online focus groups
7.	Davis et al. (2009)	Discover important aspects and domains to measure quality of life for adolescents with cerebral palsy	Seventeen adolescents aged 13 to 18 years	Grounded Theory using interviews
8.	Dew, Llewellyn, and Balandin (2014)	Examine how relationships are affected by earlier life experiences of older adults with moderate to severe cerebral palsy and their non-disabled siblings	Twelve adults with moderate to severe cerebral palsy and 16 of their non-disabled siblings	Constructivist Grounded Theory using interviews
9.	Howland and Rintala (2001)	Investigate the dating behaviors of women with physical disabilities and the barriers and facilitators faced	31 women with a variety of physical disabilities	Phenomenology using in-depth interviews
10.	Lilienfeld and Alant (2005)	Evaluation of a peer-training program aimed to train adolescents to communicate with their peers who use AAC	One boy with complex communication needs and using AAC	Phenomenology using interviews and participant observation
11.	Murphy, Molnar, and Lankasky (2000)	Research people with cerebral palsy and their social and employment opportunities	101 adults with cerebral palsy, aged 27 to 74 years, living independently in the community	Cross-sectional using questionnaires and interviews
12.	Rintala et al. (1997)	Understand the difference in dating experiences between women with and without physical disabilities and factors influencing their experiences	430 single women (250 with disabilities)	Cross-sectional using questionnaires and interviews
13.	Shuttleworth (2000a)	Explore the pursuit of sexual intimacy of men with cerebral palsy	14 Men with cerebral palsy and 17 supporters	Phenomenology using interviews and participant observation
14.	Shuttleworth (2000b)	Explore the facilitators and barriers men with cerebral palsy face when attempting to date and progress a friendship into a romantic relationship	14 men with cerebral palsy and 17 supporters	Phenomenology using interviews and participant observation
15.	Thirumanickam, Raghavendra, and Olsson (2011)	Compare the patterns of participation and social networks of children without disabilities and children with complex communication needs	Children six to nine years of age, five with complex communication needs and five without disabilities	Cross-sectional using questionnaires and interviews

2.4.1 Characteristics of Participants

The 15 papers included a total of 875 participants. This count excludes the participants in Shuttleworth (2000b) because this study had the same set of participants as Shuttleworth (2000a). Four hundred and ninety-one participants indicated having disabilities. Of these, 116 were males, 375 females, and 239 had congenital disabilities. Of the 156 identified as having a communication disability and a physical disability, only one-third reported using various AAC strategies, ranging from communication boards to speech-generating devices to communicate. Only one participant identified as homosexual.

Three hundred and eighty-four participants did not, or were not, identified as having a disability. K. Anderson et al. (2011) had six school-age friends of student peers who used AAC. Thirumanickam et al. (2011) matched five school-aged children with five other children with complex communication needs. Three studies had a total of 160 parents of children who used AAC (Angelo et al., 1996; Davis et al., 2009; Lilienfeld & Alant, 2005). Dew et al. (2014) investigated the views of 16 siblings of 12 adults with complex communication needs. Rintala et al. (1997) surveyed 180 women without disabilities. Shuttleworth (2000a, 2000b) interviewed 17 supporters of 14 men with cerebral palsy, including friends, family members, ex-girlfriends, support workers and therapists, some of whom also had disabilities. However, limited details of these supporters were provided to protect their identities. Therefore, it was not possible to isolate the number of people without disabilities in the sample.

2.4.2 Quality of Studies

The first author appraised each study, using the McMaster appraisal tools, and the two co-authors independently assessed three randomly selected studies each. The quality scores for the six papers were compared with the first author's appraisal. The percentage of agreement and Cohan's Kappa scores were calculated. With the second author, agreement was 86% with a Kappa of 0.74 and for the third author, the agreement results were 83% and 0.66. According to Viera and Garrett (2005), both scores indicate substantial agreement. Discrepancies were discussed and consensus was reached on all but one of the studies. The authors did not reach agreement on whether Shuttleworth (2000a) provided a clear and complete description of the site at which the research was conducted.

The 11 qualitative studies were appraised using the McMaster qualitative appraisal tool (K. Anderson et al., 2011; Ballin & Balandin, 2007; Collier et al., 2006; Cooper et al., 2009; Dattilo et al., 2008; Davis et al., 2009; Dew et al., 2014; Howland & Rintala, 2001; Lilienfeld & Alant, 2005; Shuttleworth, 2000a, 2000b). The maximum appraisal score was 22 and the results ranged from 11 to 19 with a mean of 16 with higher scores indicating better quality. These studies can be considered to be in the middle range of quality (Andersson, Bellon, & Walker, 2016). Each clearly stated the purpose of the research and the majority presented a review of the relevant literature. Only three papers specified a theoretical perspective, Dew et al. (2014) used symbolic interaction and Shuttleworth (2000a, 2000b) used an existential–phenomenological approach. Six papers addressed the issue of informed consent (K. Anderson et al., 2011; Ballin & Balandin, 2007; Cooper et al., 2009; Dattilo et al., 2008; Davis et al., 2009; Dew et al., 2014). The majority of the papers provided a description of the research setting and a clear and complete description of participants. Yet, most papers scored low in the descriptive clarity section of the appraisal tool. Only four papers provided details of the researchers' relationships with their participants (K. Anderson et al., 2011; Cooper et al., 2009; Shuttleworth, 2000a, 2000b) and three of the papers discussed the assumptions and biases they brought to their research (Collier et al., 2006; Shuttleworth, 2000a, 2000b).

Four quantitative research papers were appraised using the McMaster quantitative appraisal tool (Angelo et al., 1996; Murphy et al., 2000; Rintala et al., 1997; Thirumanickam et al., 2011). As the studies used surveys or questionnaires and did not include intervention, the outcomes and intervention sections of the tool were not used. The total score was out of a maximum of 12 points. One paper scored five, another seven and two scored eight, indicating poor to average quality. All the papers provided clear explanations of the purpose of their studies, with the majority reviewing relevant background literature. Only Thirumanickam et al. (2011) indicated that human research ethics approval was obtained. Half the papers specified that informed consent had been obtained and described the method used to obtain it.

2.4.3 Extracting of Data

The first author extracted and coded data from each study. Only information that could be directly attributed to participants meeting the criteria was included. In some studies, relevant data were difficult to extract because it was unclear which results were directly linked to the participants with physical and communication disabilities (e.g., Davis et al., 2009; Murphy et al., 2000; Rintala et al., 1997). Howland and Rintala (2001) discussed many barriers and facilitators to dating, yet the authors did not relate the findings specifically to their participants with communication disabilities.

Three studies, Dattilo et al. (2008), Lilienfeld and Alant (2005) and Thirumanickam et al. (2011), focused on barriers to participation, but had little to say about social relationships. Likewise, Angelo et al. (1996) and Dew et al. (2014) provided little detail on facilitators and barriers to social participation. Data more relevant to the research question were found in four papers: Cooper et al. (2009) and Ballin and Balandin (2007) on loneliness among people with cerebral palsy, K. Anderson et al. (2011) on existing friendships, and Collier et al. (2006) on sexual abuse among people who use AAC. Shuttleworth (2000a, 2000b) is the only researcher who provided rich insights into the struggles of men, most of whom had communication disabilities, in finding sexual intimacy.

Information related to the perceived barriers and facilitators to relationships and sexual intimacy was used to populate a table, including any relevant conclusions and recommendations for further research. This was analyzed and categorized into six themes: social participation, social networks, relationships and sexuality, access to sexual health care and support services, body language and image, and sexual activities and dating. Each of these themes is discussed below.

2.4.4 Social Participation

The literature identified a number of factors that affect the social participation of people with communication and physical disabilities. Facilitators included the use of AAC strategies, communication assistants and telecommunications (Cooper et al., 2009; Dattilo et al., 2008). Several papers discussed communication affecting social participation, and Dattilo et al. (2008) reported that many people with physical and communication disabilities had limited opportunities to socialize and form friendships. The literature highlighted different influences on these opportunities.

The participants in Ballin and Balandin (2007) reported that public places such as bars, churches and social clubs can be places to socialize, but pose limited opportunity for people with complex communication needs. Such places can reinforce the feeling of loneliness because of excessive noise and poor public disability awareness. Although friends and neighbours can provide valuable support for someone with complex communication needs, they can also impede social interactions due to a lack of disability awareness (Ballin & Balandin, 2007). Even parents who are supportive can have a negative effect on the abilities of their child to form future intimate relationships, for example, through attitudes or behaviours that unintentionally impose restraints and lower expectations for marriage and a sex life (Howland & Rintala, 2001; Shuttleworth, 2000a). Therefore, it is important to maintain support throughout the lives of people with physical and communication disabilities to achieve such future relationship outcomes (Cooper et al., 2009). Research has demonstrated that providing disability-awareness training to potential communication partners, including instruction on how to communicate with a person who uses AAC, can increase opportunities for people with complex communication needs to expand their social circles (K. Anderson et al., 2011; Ballin & Balandin, 2007; Lilienfeld & Alant, 2005).

According to Dattilo et al. (2008), people broaden these limited social opportunities by using support workers, friends or family to assist in preparation and transport to social events, as well as acting as communication assistants. While communication assistants can be facilitators in conversations within social settings such as churches, hotels, and social clubs, the additional person can create a hindrance simply through their presence (Dattilo et al., 2008; Shuttleworth, 2000b). Their presence changes the dynamics of social situations and can impede the person with disability meeting and interacting with others (Dattilo et al., 2008). For people requiring assistance to access text messages and make calls on their mobile telephones, Cooper et al. (2009) warned that the person assisting should only facilitate the communication and ensure that they do not become a part of the conversation. The authors again highlighted that the extra person can compromise privacy and as a result, hinder the development of relationships.

Access to appropriate AAC has been demonstrated to support the development of autonomy and self-advocacy in social interactions, factors that are vital to people with complex communication needs entering adulthood (Cooper et al., 2009). As Gloria, a participant in Cooper et al. (2009) stated, “AAC has really advanced my relationships with family and friends. Without AAC I would not be able to talk to people independently” (p. 158). AAC users argued that access to AAC plays a vital role in forming and developing social relationships (Cooper et al., 2009; Dattilo et al., 2008), as well as in combatting loneliness (Dattilo et al., 2008). However, participants expressed frustration that generating messages using their devices can be very slow, making conversation difficult. Many participants expressed frustration at needing more time to communicate, yet seldom obtaining this time, reporting that conversations often have advanced to other topics by the time they have generated their responses (Ballin & Balandin, 2007; Cooper et al., 2009).

Moreover, communication devices do not adequately support users in their social interactions (Dattilo et al., 2008). This inadequacy can be due to a lack of appropriate vocabulary (Collier et al., 2006), including a lack of age-appropriate communication support (K. Anderson et al., 2011). People might be efficient at using their AAC, yet a breakdown in communication can occur if their communication partners lack skills in communicating with someone using AAC (Cooper et al., 2009; Lilienfeld & Alant, 2005). Poor literacy skills of the AAC user, the communication partner, or both, can also interfere with successful social interactions (Cooper et al., 2009).

Telecommunications such as telephone, email, short message service (SMS) and social-networking sites can assist people who use AAC to develop and maintain social relationships (Cooper et al., 2009; Dattilo et al., 2008). These media also enable non-disabled and disabled siblings who live far apart to support each other (Dew et al., 2014). AAC users report telecommunication can be difficult to use because of accessibility issues (Ballin & Balandin, 2007; Cooper et al., 2009) and there is a need for more research into improving telecommunications access to progress social relationships and minimize loneliness for people with physical and communication disabilities (Cooper et al., 2009).

2.4.5 Social Networks

Forming and maintaining social relationships are recognized in the literature as requiring effective lifelong support networks. These should include friends, neighbours and family, and support workers (Ballin & Balandin, 2007). The three core methods discussed as assisting people with physical and communication disabilities to develop and sustain their support networks were buddy systems in schools, educational support for families, and social support through adulthood.

Within a school setting, K. Anderson et al. (2011) investigated a buddy system where one of the buddies had complex communication needs. The research investigated the perspectives of the buddies without disabilities. The stories of the non-disabled students describing their friendship with their peers with complex communication needs revealed that the friendships formed were genuinely beneficial to both parties, and increased the socialization of the students using AAC. However, the authors noted that strain can occur in friendships when the boundaries between friendship and carer responsibilities become blurred and expectations are mismatched.

For families with children who use AAC, providing educational support for involvement in a wide range of activities helps promote autonomy and independence (Thirumanickam et al., 2011). Adolescent participants in Dattilo et al. (2008) reported that “their families were supportive, inclusive, and innovative and that they pushed them to be involved and independent” (p. 24). Dew et al. (2014) argued that because adults with cerebral palsy who use AAC are less likely to have children of their own, they typically rely on family support longer than people without disabilities. Therefore, the authors urged service providers to provide support to build and maintain relationships and social networks (Dew et al, 2014). Given that siblings often take over from ageing or deceased parents in providing support, researchers have suggested that service providers also support families to plan for the future to ensure that siblings using AAC can maintain their friendships and social networks throughout their lives (Dew et al., 2014).

Collier et al. (2006) encouraged research into discovering methods of lowering the social isolation of AAC users. A number of other researchers have recommended future research into developing and maintaining social networks of people with complex communication needs across their lifespan (e.g., K. Anderson et al., 2011; Angelo et al., 1996; Ballin & Balandin, 2007; Cooper et al., 2009; Dew et al., 2014). Specific research suggestions on improving social networks have included investigating methods to improve the delivery of support to families across the lifespan of their offspring with physical and communication disabilities (Angelo et al., 1996); exploring the social networks of young adults with cerebral palsy, in particular the role of family and friends (Cooper et al., 2009); investigating effective methods for adults and children with disabilities in developing long-term and stronger relationships (K. Anderson et al., 2011; Ballin & Balandin, 2007; Dew et al., 2014); and evaluating the effectiveness of disability-awareness education and the effect life milestones have on friendships and long-term relationships (K. Anderson et al., 2011). Despite policies that prohibit support workers and their clients from developing relationships beyond the professional, such relationships often develop into friendships (Ballin & Balandin, 2007; Collier et al., 2006; Shuttleworth, 2000a) and enable social connection with mutual benefits (Ballin & Balandin, 2007; Shuttleworth, 2000b). The adults who used AAC in Ballin and Balandin (2007) indicated the importance of being able to discuss personal issues and gain emotional support from their support workers. Ballin and Balandin (2007) suggested that the "possibility of reciprocal feelings of friendship [developing] between older adults […] and staff must […] be acknowledged" (p. 322). These authors also noted that a high turnover of staff in residential settings can prevent meaningful friendships and relationships from developing between adults with disabilities and their support workers, stating that it is "clear that facilitating the friendships and social network development of older adults […] is important in ensuring that these individuals maintain a satisfying lifestyle as they age" (p. 324).

2.4.6 Relationships and Sexuality

Relationships and sexuality have been identified as two of the essential factors that contribute to quality of life for adolescents with cerebral palsy (Davis et al., 2009). Forming sexual identities and learning the etiquette of relationship building usually occurs in youth through socializing with peers (Shuttleworth, 2000b). However, people with physical and communication disabilities often lack adequate sexual and relationship education in their youth (K. Anderson et al., 2011; Collier et al., 2006; Howland & Rintala, 2001; Murphy et al., 2000; Shuttleworth, 2000a). Adolescents who use AAC frequently miss opportunities to discuss essential topics for their development such as sexuality, intimacy and relationships with peers and support workers (K. Anderson et al., 2011; Collier et al., 2006). The participants in Collier et al. (2006) expressed strong feelings of being deprived of information about healthy relationships, opportunities for experiencing intimate relationships and being able to express their own sexuality. The participants perceived that support workers, parents and doctors saw them as asexual and as a result, not in need of such information. One participant in Collier et al. (2006) highlighted this perspective: “I wish I had been taught about women and having a girlfriend, and being a parent. I think families should talk to their kids with disabilities about sex, bodies, HIV/AIDS, relationships, and love” (p. 69).

Self-esteem plays an important role in developing relationships (Rintala et al., 1997; Shuttleworth, 2000b). K. Anderson et al. (2011) suggested that positive personal qualities of students who use AAC were useful in building and maintaining friendships with non-disabled students. However, Dattilo et al. (2008) found that at times, adults with complex communication needs create self-imposed barriers that can hinder social interactions, including being afraid of trying new activities, being frustrated at their lack of perceived ability to participate in conversation, and feeling vulnerable in certain social settings. Similarly, Rintala et al. (1997) identified that low self-esteem in women with communication disabilities can affect their ability to communicate effectively in a dating situation, which further lowers their self-esteem and exacerbates barriers to social participation.

The men in the Shuttleworth (2000a) study revealed that they experienced difficulties in navigating adult intimate relationships despite participating in mainstream society. In particular, their difficulties were associated with the ability to advance the relationship to greater intimacy. Shuttleworth (2000a) suggested this could be due to lack of experience because vital socializing had been inaccessible to his participants early in life. The potential partner's concerns with how they would be seen by others, or unconscious perceptions of the men as being asexual may also have contributed to the participants' difficulties in pursuing greater intimacy (Shuttleworth, 2000b). Earlier onset of physical disabilities can result in poorer dating experiences (Howland & Rintala, 2001; Rintala et al., 1997). For example, a participant in Howland and Rintala's (2001) study was a middle-aged woman with cerebral palsy who used AAC and was attracted to a disc jockey. She wrote him anonymous letters and often telephoned him and hung up when he answered. Such actions demonstrated her lack of development of age-appropriate skills that could be attributed to her having missed opportunities to develop relationships in her teens.

2.4.7 Access to Sexual Health Care and Support Services

In maintaining healthy relationships and wellbeing, accessing health and support services for sexual health can be difficult for people with complex communication needs (Collier et al., 2006). These difficulties include "physical accessibility and lack of background training for service providers in issues relating to disability, communication, sexuality, and abuse" (Collier et al., 2006, p. 69). People frequently use their support workers to assist with access to appropriate services in these settings and to facilitate communication (Ballin & Balandin, 2007). However, Collier et al. (2006) asserted that there are privacy and flexibility issues with having to use support workers who are part of the person's regular support team to facilitate communication on personal matters. The researchers recommended that improved sex education and sexual health information be available to young people with disabilities, enabling them to enhance their relationships and empowering them to protect themselves from abuse. Their participants indicated personal benefits from being involved in a research project that allowed them to discuss issues of relationships and sexuality with other AAC users. Further, participants expressed the need for role models who have disabilities to support their learning about dating, forming relationships and becoming intimate, yet such role models are absent in the media and sparse in everyday life (Shuttleworth, 2000b). Shuttleworth (2000a) emphasized the importance of having access to counselling on sexuality and relationships for people with disabilities.

Collier et al. (2006) argued that people who use AAC could face additional barriers to communicating within sexual health services due to the limited vocabulary in their communication devices. A participant in her thirties was concerned about a condition termed "spastic bladder"—a condition common in people with cerebral palsy—and whether it could interfere with sexual activity. However, the limited vocabulary in her AAC device meant it was difficult to discuss this issue with a health care provider (Collier et al., 2006). AAC clinicians have significant power over the vocabulary available and can indirectly affect access of AAC users to sexual health services. It is essential to provide adequate vocabulary to enable people to discuss matters of sexuality, including abuse, with professionals such as counsellors and sexual health providers (Collier et al., 2006).

2.4.8 Body Language and Image

Body image and the use of body language by people with physical and communication disabilities in searching and maintaining intimate relationships have only been addressed in four papers—Shuttleworth (2000a, 2000b) being the principal investigator in these areas. The men in Shuttleworth's research (2000a) acknowledged that in our society, body language and image play an important part in forming and maintaining sexual relationships, and indicated that they find it difficult or impossible to conform to the body image promoted as attractive by the popular media in Western society. They perceived this unachievable image as an impediment in their search for sexual intimacy (Shuttleworth, 2000b). Shuttleworth (2000a) examined some of the struggles men with cerebral palsy faced when their physical bodies did not conform to such standards. For example, one of the men reported his perception that his dysarthric speech was a barrier to expressing himself, particularly when meeting new people. Another participant responded about approaching women in public places using his communication board. He believed strangers would misinterpret his body movements and might not read the board. A different participant believed that irrespective of his speech, the way others and he saw his body had an effect on his relationship opportunities. Spasticity in cerebral palsy can become worse when the person is nervous and is attempting to minimize involuntary movements, for example, in the simple act of trying to put an arm casually around another. These movements (of both the face and body) can be seen by people with cerebral palsy as further barriers to being attractive (Howland & Rintala, 2001). A participant in Ballin and Balandin (2007) stated, “I miss touching. Why must we go without touching? Sex too. People don’t see me in that way. They only see my chair first” (p. 321).

2.4.9 Sexual Activities and Dating

Only three papers, Collier et al. (2006) and Shuttleworth (2000a, 2000b), discussed assistance with sexual activities and assistance on dates. Collier et al. (2006) reported that “[a]ssistance with sexual activities may include support in preparation, positioning, using safer sex supplies, birth control and set-up for masturbation” (p. 68). Once again, assistance of support workers was reported as a facilitator and a barrier to such activities. Each of these three papers raised the issue of the ability of people to participate in sexual activities and the policies surrounding support workers providing assistance. They identified that although these policies provide protection for the clients, support workers, and service providers, they could inhibit the assistance people require with sexual activities. As Collier et al. (2006) asserted, these types of policies are often non-existent or not well known, leaving people vulnerable. For this kind of assistance to be provided and for privacy to be maintained, the trustworthiness of clients and support workers is paramount. More importantly, there must be a high level of willingness from support workers because in most cases where they support their clients' intimate relationships, it is necessary to "bend the rules" (Collier et al., 2006; Shuttleworth, 2000a, 2000b).

Shuttleworth (2000a) reported that support workers assist their clients to socialize and develop intimate relationships. Dates can be complex events for anyone and Shuttleworth's participants raised the dilemma of needing a support worker on dates. The options are to take a support worker on the date to assist with personal needs such as eating and toileting, or to ask the date to assist, requiring negotiation by both parties. However, Shuttleworth (2000a) suggested that personal care being provided by the date or partner is a contributing factor to relationship breakdowns because they have to negotiate how their basic needs are met. Nevertheless, Shuttleworth (2000a) maintained that despite the limiting policies associated with support services, a valid option for seeking sexual intimacy could be developing a relationship with a support worker.

Shuttleworth (2000a) was the only study reviewed that offered a useful, practical dating technique for a person with physical and communication disabilities to consider and use in the pursuit of intimacy. Although the usual dating techniques such as flirting and placing advertisements in local papers have been attempted by his participants, "some of the older men with speech impairments said that using one's face and body to communicate was very important" (Shuttleworth, 2000a, p. 190). This included using eyes to be suggestive, using humour to put women at ease and offering a back rub as practical dating strategy. The men perceived difficulties in using their bodies in their attempts to court women. Nevertheless, they reported back rubbing as a technique to create intimacy and as a facilitator to help overcome barriers to intimacy. A participant who uses his feet instead of upper limbs and uses an AAC device, often relies on a successful pickup line, offering to give women back rubs with his feet. Another who has a severe physical disability, adapts this intimacy technique and asks for a back rub from his date. Shuttleworth's (2000a) study highlighted methods people with disabilities can use to advance their intimate relationships.

2.5 Discussion

This review aimed to identify perceived barriers and facilitators experienced by people with both congenital physical and communication disabilities in their desire to socialize, share intimacy, and express sexuality. Thematic analysis of 15 studies revealed that the majority of the literature focused on the needs of people with physical and communication disabilities in developing friendships and social networks. The six themes that emerged were social participation, social networks, relationships and sexuality, access to sexual health care and support services, body language and image, and sexual activities and dating. However, the papers did not directly address perceived barriers and facilitators to relationships and sexual intimacy.

This review faced several challenges arising from the failure of some of the studies to separate data by disability type. The descriptions of participants were often ambiguous in relation to physical and communication disabilities. This made it difficult to assess and extract data relevant to the research question. For example, in some papers, a proportion of the participants were identified as having communication disabilities but the researchers provided very little or no findings that could be directly attributable to such participants. Rintala et al. (1997) stated that of 250 women with a disability, 34 had "difficulty having speech understood" (p. 226). Yet, the speech difficulties that the participants experienced were not clearly defined, and no further explanation was provided of the meaning of "speech problem". Therefore, only data that could be directly attributed to people with physical and communication disabilities were analyzed in this review.

The majority of the papers reviewed focused on social participation in different environments (e.g., daily living skills, education and employment outcomes), rather than on intimacy and sexuality. Social isolation, overprotective environments and poor education may lead to a lack of opportunity for people with complex communication needs to develop the social skills necessary to develop intimate relationships. Light and McNaughton (2015) argued that it is necessary to place greater focus on supporting communication to build healthy sexual relationships.

It appears there is often a crossover between barriers and facilitators, with many of the facilitators (e.g., AAC strategies, mainstream technology, and friends and family) also identified as forms of barriers. For example, although parents were identified as supportive, it was also stated that they could limit opportunities and unintentionally impose restraints by communicating their low expectations for marriage and a sex life.

The lack of opportunity to explore sexuality and poor access to sexual health services was identified a decade ago (e.g., Collier et al., 2006). This review has highlighted the continuing unmet need for improved education and access to services, which could result in healthier relationships for people with physical and communication disabilities and empowerment to prevent sexual abuse.

It seems that little is known of the experiences that people with complex communication needs face in developing romantic and sexual relationships. Only one-third of the papers specifically investigated the romance and dating experiences of people with disabilities (Howland & Rintala, 2001; Rintala et al., 1997; Shuttleworth, 2000a, 2000b).

Only Shuttleworth's (2000a) research of a majority of participants with complex communication needs reported practical techniques that participants had successfully used to develop intimacy.

The literature calls for counselling on sexuality and relationships, and access to sexual health services. It seems people with physical and communication disabilities would also benefit from personal coaching in the field of dating and expressing sexuality. Further research is required to provide a framework for policies that would enable support workers to assist people with physical and communication disabilities in developing intimate relationships and sexual experiences.

This review demonstrates the need for further qualitative studies on the experience of people with complex communication needs in developing romantic and sexual relationships. The low to medium McMaster critical appraisal scores of the studies draw attention to the need for high-quality research with greater rigour within this field, a gap that could have been addressed by the provision of more detailed contextual data. Future research could benefit by including more background information on participants, including the type of disability and living arrangements of participants. Such research will not only assist in policy and service-delivery development but will also educate and inform lovers with physical and communication disabilities. More research investigating the dating experience of people with complex communication needs would be useful for AAC practitioners, researchers and people with complex communication needs seeking intimacy.

2.6 Limitations

All systematic reviews are subjective to some extent due to the way in which reviewers construct their criteria and make decisions on the topic under investigation (Alwell & Cobb, 2009). As sexuality and intimacy (the topic of this review) can be discussed using a variety of different terms, it was necessary for the search strategies to be quite broad to ensure relevant studies were found. The search strategies were primarily restricted to peer-reviewed studies in the English language and did not include grey literature.

A pearl search (a search of reference lists of relevant papers to locate further relevant studies) was not conducted. The findings of this review should be utilized with caution as the studies were drawn from many disciplines and only a small number met the inclusion criteria.

2.7 Conclusion

Although there is a body of literature surrounding disability and sexuality, this review highlights that there is little directly relevant research addressing intimacy and sexuality which can be referred to by people with physical and communication disabilities, AAC practitioners and researchers. The quality of the research identified was not high. Most of the literature focused on supporting people in social networks and on protection from abuse, and some called for improved counselling on sexuality and relationships, and access to sexual health services. As with the majority of research, the representation of people with complex communication needs was poor and the people in this group rarely had the opportunity to contribute to the research.

There is a need for further high-quality research that focuses on practical and theoretical outcomes to enhance social relationships and sexuality, as well as offer lovers who use AAC real advice in their search for intimacy.

3 Literature review

People with complex communication needs aspire to socially-valued roles, as students, employees, employers or academics, as well as sexual beings and lovers (Bryen, 2008). Because they have a physical or intellectual disability along with limited functional speech for everyday communication, it is vital for them to have communication skills to enable them to share with others and to foster relationships (Collier et al., 2010). Over 40 years ago, the Augmentative and Alternative Communication (AAC) field began to address the unmet needs of people with complex communication needs (Alant, Bornman, & Lloyd, 2006).

The AAC field endeavours to support people with complex communication needs to live their lives to their full potential by providing evidence-based interventions for their daily communication needs (Kent-Walsh & Binger, 2018). This relatively young field has matured into a vibrant international community of AAC practitioners, teachers, technology providers and manufacturers, and people who use AAC to communicate. There have been numerous AAC research publications where at least one of the co-authors had a disability (eg., Blackstone et al., 2007; McNaughton, Bryen, Blackstone, Williams & Kennedy, 2012; Rackensperger, Krezman, McNaughton, Williams & D'Silva, 2005). The majority of the research and practice in this field has concentrated on developing language and communication skills, education, living skills, social networks and employment (Light & McNaughton, 2015). Research has highlighted the importance of accurately documenting the words of people with complex communication needs, but “there is little to no tradition for providing written representations of conversations involving people using alternative means of communication” (Von Tetzchner & Basil, 2011, p. 148).

The AAC field is based largely on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, United Nations, 2006). Article 23 of the Convention affirms the rights of people with disabilities to participate in family and social adult relationships, including romantic and sexual relationships. With the absence in the literature of the lived experiences of people with complex communication needs in developing romantic and sexual relationships, it is evident that the field is not yet fulfilling this aspect of the Convention. People with complex communication needs lack access to appropriate evidence-based interventions to assist them in forming adult relationships.

This chapter commences with a description of the key terms used in this thesis and presents an overview of the literature concerning romantic and sexual relationships more broadly. It then explores the disability movement and the theoretical models that have been used to understand disability. It discusses the power of the State over the lives of people with disabilities, in particular over their private lives. This is followed by an exploration of the literature in both the Disability and Sexuality fields. The chapter then leads to a discussion on communication and participation challenges for people with complex communication needs who use AAC within social relationships. The rationale for the current study is then summarised, along with the aims of the study.

The systematic review (Sellwood et al., 2017) presented in the previous chapter, demonstrated that, compared to the wealth of literature in the broader Disability and Sexuality field, there are a limited number of research studies within the AAC field on the lived romantic and sexual experiences of people with complex communication needs. It identified that the AAC-related literature on sexual matters tended to be concerned with protection from abuse rather than with sexual participation. The few authors who did approach the topic recommended improved counselling on sexuality and relationships, and asserted that access to sexual health services for people with complex communication needs is required to encourage the development of romantic and sexual relationships.

3.1 Romantic and Sexual Relationships

To provide context for this discussion, it is helpful to first examine the nature of romantic and sexual relationships. These types of non-platonic relationships are usually formed between two individuals for perceived personal benefits. Jonason and Balzarini (2016) suggested that people can have multiple types of relationships to meet their numerous emotional and physical needs, and that "individuals derive several benefits [from] engaging in relationships, including sexual gratification, socioemotional support, relief of boredom, and to raise […] self-esteem" (p. 16). These types of relationships require the ability and opportunity to identify potential intimate partners, to interact with people and to form social relationships (Oudekerk, Allen, Hessel, & Molloy, 2015; Simon, Aikins, & Prinstein, 2008).

The traditional western view of intimate relationships is changing. Aumer (2016) argues that the theme "love and hate" frequently appears in popular culture, such as songs and films. Where once intimate relationships were perceived as "heterosexual, monogamous, full of unconditional love, and male sexually dominated" (p. 2), this is no longer the case as social norms and social acceptance are evolving. The concept of a relationship as being ideally monogamous is grounded in Christianity, specifically Catholicism, rooted in Bible verses. Aumer (2016) questions whether this is an ideological view of human romantic relationships rather than reflective of their true nature. Even the practice of dating is changing; with increasing usage of online technology including social media and dating websites, it has become less formal and more casual in structure (Aumer, 2016).

Research into romantic relationships has historically focused on the pathological issues surrounding these relationships until recent social science research broadened the scope (Aumer, 2016). A content analysis of literature published between 1960 and 2013 on romantic relationships in the four prestigious journals, *The Journal of Sex Research, Archives of Sexual Behavior, The New England Journal of Medicine, and Obstetrics and Gynecology,* revealed that only 3% of published articles were found to be positive towards romantic relationships as most of the literature addressed problem sexual behaviour (Arakawa, Flanders, Hatfield, & Heck, 2013). Jonason and Balzarini (2016) asserted, in reviewing research conducted on the types of romantic relationships over the past half century, much of the literature had an emphasis on monogamous long-term romantic relationships and portrayed casual sex as pathological. Furthermore, much of the literature focussed on the risk of expressing sexuality rather than understanding the broad spectrum of human sexuality. The authors noted that it was not until after 2010 that literature started to include research on casual sexual relationships.

Jonason and Balzarini (2016) suggested that society's perception of types of relationships is evolving from a dichotomy where relationships were seen as either traditional and formal or as casual sexual encounters. The authors described traditional relationships as "formal," which includes dating and marriage with "traditional" reasons of love, procreation, or commitment, and "casual sex as sexual activities (e.g., mutual stimulation, oral sex, or sexual intercourse)" (p. 17) outside the traditional relationships. These two descriptions do not encompass the range of relationships which involve romantic and/or sexual relations, for example "booty call" is a term used to describe relationships between friends who occasionally have sex together without romantic ties (Jonason & Balzarini, 2016). This is more commonly known as "friends with benefits," which implies a friendship with some degree of intimacy. This can be distinguished from "hook-ups" which tend to be transitory, non-committal, sexual relationships between individuals, often strangers or acquaintances (Jovanovic & Williams, 2018). The literature which describes sexual relationships that are perceived to be outside the current social norm tends to be negative on the whole and warns of the risks involved. Some researchers have argued, however, that there may be some benefits to these casual interactions, citing evidence which suggests that people may use casual sex as a stepping stone to exploring a deeper relationship (Jonason, Luevano, & Adams, 2012).

Because they can be used to develop a romantic relationship out of a platonic friendship, these sorts of relationships have become popular within the emerging adult population (Weger, Cole, & Akbulut, 2018). However, research seemed to show a difference in expectations between the genders. In a study of 106 university students in "friends with benefits" relationships, Jovanovic and Williams (2018) suggested that the majority of the female participants felt more constrained than the males by socially constructed sexual norms. It may be that this has its roots in the way the genders develop their sexual identities through communication with their peers. According to Policarpo (2017), in a study of 35 people of both genders aged 30–55, young people learn social norms and how to form relationships through talking about their experiences and emotions within their circle of friends. The male participants were competitive, wanting to outperform their peers, focused on managing their relationships, and were more strategic in their interactions. The females were more concerned about the need to belong, to have a sense of control within their group of friends, and to have a place to escape from the social norms. They were more concerned with managing their identities than with challenging social norms. In the discussion regarding the differences in relationships and between genders, the literature fails to address the impact of disability on romantic or sexual relationships.

3.2 Disability

To provide cultural context, which is required when using a critical hermeneutics approach, it is useful to provide a brief description of the disability movement, and the models that have been used in research and practice. It is also worth considering the recent introduction of the Australian National Disability Insurance Scheme (NDIS), which is aimed at ensuring that people with disabilities have choice and control in their lives. Within the

Disability field, it is well documented that people with disabilities face additional challenges in developing romantic and sexual relationships (Bahner, 2018; Bennett, 2017; Collier, McGhie-Richmond, Odette, & Pyne, 2006; Czapla & Otrębski, 2018; Esmail, Darry, Walter, & Knupp, 2010; Goldberg, 2018; Loeser, Pini, & Crowley, 2018; M. McCabe & Taleporos, 2003; Sellwood et al., 2017; T. Shakespeare & Richardson, 2018; Shildrick, 2009; Shuttleworth, 2012; Wiegerink, Stam, Ketelaar, Cohen-Kettenis, & Roebroeck., 2012). As the understanding of disability has evolved, the focus has shifted from a rehabilitation to a rights-based perspective—improving the lifestyle and satisfaction of people with disabilities.

3.2.1 Disability rights and models

Prior to discussing the issue of disability and sexuality in more detail (see section 3.3), it is important to trace the emergence of the disability rights movement and current conceptions of disability, to give historical context to the issues discussed in this research. According to the World Health Organization (2011), "Disability is complex, dynamic, multidimensional, and contested" (p. 3). There has been debate around the definition of disability since the 1960s within the Disability field which includes social and health science researchers and activists (Oliver, 2017; World Health Organization, 2011). The *Convention on the Rights of Persons with Disabilities* states that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 1). Due to negative attitudes, people with disabilities have a history of being seen as less valued and have often been pushed out to the fringes of society (Barnes, 2003; Oliver, 1996; T. Shakespeare, 2017). Beginning with the industrial revolution, people with disabilities who did not fit into a productive job were seen as needing to be "fixed" or be taken away to be cared for, with the focus predominantly on their impairment. Since the early twentieth century, research relating to people with disabilities was predominantly focused on biological impairments or socially-constructed discrimination (Barnes, 2003; Oliver, 1996; T. Shakespeare, 2017).

3.2.1.1 Medical model

The Medical Model was one of the first, and remains a dominant, model of disability. It emerged from the medical profession and focused on the impairments of individuals with the intention to rehabilitate. The assumption was that the person's impairment, be it physical, sensory or intellectual, caused the disability and medical intervention was essential. The model had as its core belief that it was necessary to reduce an individual's impairments so that they could live a "near normal" life (Thomas, 2002). Services for people with disabilities were geared towards "curing" and, if this was not possible, removing them until they could be rehabilitated to re-enter the mainstream (Hurst, 2003). The Medical Model was arguably disempowering for people with disabilities and, like other social institutions in the 1960s and 70s, the power of the medical profession was being challenged (Hurst, 2003; Thomas, 2002). A landmark film called *Don't Hurry Past: 1954 Cerebral Palsy Documentary* (Spiess, 1954), filmed in the early 1950s, challenged the predominant view of disability at the time. Although much of the language reflected a medical and charitable perspective, it demonstrated an understanding that people with disabilities could be integrated into mainstream society without the need to be 'cured'.

3.2.1.2 Social Model

Encouraged by the women's rights movement in the 1960s, people with disabilities started their own movement to challenge society's views of them. One of the key proponents of a related movement, the Independent Living Movement, was Ed Roberts, a man living with polio and who demanded the right to attend university (White, Lloyd Simpson, Gonda, Ravesloot, & Coble, 2010). Together, this groundswell of action gave rise to an alternative understanding of disability which positioned it as a problem with society, rather than with the individual and their impairment (Hurst, 2003). According to Hurst (2003), in the US and UK, groups of disabled activists were beginning to think about disability in new ways. Their awareness raising efforts promoted disabled people as having the same human rights as the general population, including to reach their potential. In UK institutions, people with disabilities questioned the segregation of services within segregated institutions.

People with disabilities were increasingly criticising the Medical Model and these activists developed a social approach to understanding disability that came to be known as the Social Model (Barnes, 2003; Oliver, 2017). The Union of the Physically Impaired Against Segregation (UPIAS) was a group of disabled British Marxists who stated, "In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society" (UPIAS as cited in T. Shakespeare, 2013, p. 215). The premise of the Social Model was that the lives of disabled people would be improved if they were integrated into society, and disabled people would become integrated into society if the social barriers were minimised or removed (T. Shakespeare, 2013).

The Social Model shifts the emphasis from the body requiring fixing to societal attitudes requiring fixing, and denies the conceptualisation of disability as being part of the person (Clare, 2001). The Social Model is not without criticism. Shildrick (2009) asserted that a risk of the Social Model is that it can reinforce normative practices and not take into account the "actual significance of differential embodiment" (p. 66). Shildrick (2009) also described other disabled scholars who questioned the Social Model's capacity to describe disability. T. Shakespeare (2017) also argued that, even with the removal of social barriers, people with disabilities are required to put in greater effort than their able-bodied peers in order to achieve.

Hannam-Swain (2018) emphasises this in her article, describing her experiences as a disabled woman trying to fit into the 'normal' way of life in the first year and a half of doing a PhD at a university in the UK. She describes how this demanded a higher degree of effort for her in comparison with her able-bodied peers, and how the systems designed to support participation can introduce further obstacles to be navigated by the disabled person. She gives an example, which is similar to the situation I have experienced in Australia, where she had two sources of funding for assistance. One was for personal care, such as assistance to get up in the morning, showering and going to the toilet, and the other provided through the university to assist her with university tasks but not with personal care. So, if she was at university at a time when she needed personal care as well as academic support, she had to coordinate for two support people to be available. Similarly, when attending conferences, although one person would have been sufficient, due to the funding requirements, she had to coordinate support so that two workers could attend.

Her article highlights the bind in which people with disabilities can find themselves. In one sense they are raised to accept their disability and taught to try to be "as normal as possible", while not being a hindrance to their colleagues, friends and family. Yet, they are expected to achieve similar outcomes to their peers despite the additional cost of their disability. Hannam-Swain (2018) ends her article by saying "Having a disability means that I am attempting to do a PhD with an extra workload which is equivalent to having another part-time job" (p. 42). This is one example which highlights that, even with funding designed to assist with removing many of these social barriers, there are additional factors that people with disabilities have to take into account while striving to enjoy basic human rights.

In his critique of the Social Model, T. Shakespeare (2017) argued that "the social model is wrong" (p. 91) because its assertion that it is society which disables, not individual impairments as such, minimises the impact of those impairments on the lives of people with disabilities. Even if all barriers to social participation were removed, the disadvantage would persist—able-bodied people can use a wheelchair if they choose, but a wheelchair user cannot choose to walk. Relating this to the current research, even though barriers can be removed by providing communication access training in their communities (Solarsh & Johnson, 2017), people with complex communication needs would still be at a disadvantage. Once they exited that community of competent communication partners they would continue to encounter social barriers, yet their communication partners would have more freedom to move in and out of that community. The Social Model arguably negates the need for therapy interventions to improve a person's communication by conceptualising the issue as a social problem. Even Oliver (1996) acknowledged that there are shortcomings to the model, yet claimed "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" (p. 17). These limitations of individual models necessitate the application of a combination of the models to yield deeper insights into the complexity of disability.

The Social Model and the Medical Model are often seen as a dichotomy, but this is not really the case. One views disability as an individual's impairment that requires addressing, while the other incorporates social and physical barriers which inhibit an individual's ability to participate in every day society. The World Health Organization (WHO) states that, due to the complexity of disability, neither model adequately represents the lived experiences of people with disabilities. Indeed, the WHO has suggested that "A balanced approach is needed" (2011, p. 4) as each perspective is useful for understanding particular aspects of disability. Acknowledging the shift in attitudes and perceptions of people with disabilities, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was developed over several decades and adopted in 2006.

3.2.1.3 United Nations Convention on the Rights of Persons with Disabilities

The Convention acknowledges that people with disabilities face additional barriers in participating in social relationships, and that there is a need to remove or mitigate those barriers.

> *"In fact we have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities. Governments throughout the world can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine," Professor Stephen W Hawking wrote in the forward of the World Report on Disability (World Health Organization, 2011, p. ix)*

In 2008, Australia was among the first countries to ratify this legally binding international treaty (Mulcair, Pietranton, & Williams, 2018). "The Convention is a human rights instrument with an explicit, social development dimension, advocating that all persons with all types of disabilities must enjoy human rights and fundamental freedoms" (p. 35). The following articles are most relevant to this research:

- Article 23 asserts that people with disabilities have the right to be part of a family and to participate in social relationships including romantic and sexual, and states that government support should be provided to parents with disabilities to perform their parental role.
- Article 25 states that people with disabilities have the right to access healthcare services equal to others, including sexual health services.
- Article 24 outlines the government's responsibility to ensure an inclusive education for all, including the need to provide communication supports for

individuals with complex communication needs; no student should be excluded from free and compulsory primary or secondary education on the basis of disability. Sex education would be considered a part of this schooling.

- Article 21 states the importance of taking appropriate steps to ensure that people with a disability have the right to say what they think and share their ideas as other people do, through all forms of communication of their choice. "Not only is communication a human right, it is the essence of what makes us human" (p. 38), and communication skills play an important role in successful participation in modern society, which includes having positive social relationships (Mulcair et al., 2018).
- Article 22 includes the right to privacy, regardless of the type of accommodation setting.

The International Classification of Functioning, Disability and Health (ICF) is a tool for governments, practitioners and researchers to provide a framework within which to apply the Convention.

3.2.1.4 The International Classification of Functioning, Disability and Health

One purpose of the ICF model proposed by the WHO is to provide a common terminology across the Health and Disability sectors (World Health Organization, 2001). The ICF is a conceptual framework of a biopsychosocial model of disability which surpasses the two predominant models of disability, the medical and social. It takes into account that "disability is characterized as the outcome of a complex relationship between an individual's health condition and personal factors, and of the external factors in the individual's environment, thus highlighting the interactive nature of the model" (Raghavendra, Bornman, Granlund, & Björck-Åkesson, 2007, p. 352). The model is increasingly being used within the field of AAC in clinical and research practice (Fried-Oken & Granlund, 2012). It assists AAC practitioners and researchers to consider both personal factors and environmental factors, in acknowledging the interactions between body structure, function and activity. It provides a framework for designing interventions and research, to contribute to improved participation outcomes for AAC users by emphasising and enhancing their capabilities within their various environments (Light & McNaughton, 2015). The ICF's clear hierarchy of components and the chapter headings provide researchers with a framework for designing qualitative and quantitative research (World Health Organization, 2013).

The ICF introduces a key component, participation, and defines it as the involvement of a person in life-situations (World Health Organization, 2011). Participation is conceptualized as more than simply being present, involving active engagement in the community (Balandin, 2011). It is multi-dimensional, highlighting the relationship among impairment or limitations of activity, environmental and contextual factors. The environment, such as, AAC devices that direct support workers as opposed to steps preventing access to buildings, can impact greatly on a person's ability to participate in tasks. These factors can be broad ranging and not exclusively about barriers pertaining to physical accessibility or access to information (World Health Organization, 2001). They can include issues associated with policy and service providers. Mainstream systems do provide services to people with disabilities, but because they are designed for able-bodied people, they frequently do not allow for the extra requirements of people with disabilities (World Health Organization, 2011). The NDIS has been established in the attempt to enhance the active participation of Australians with disabilities in all aspects of society.

3.2.2 Australia's Response: National Disability Insurance Scheme

The Australian NDIS is a major social policy shift in the provision of support for people with disabilities in Australia. It is part of Australia's response to the UNCRPD (Goggin & Wadiwel, 2014) and the *Disability Care and Support: Inquiry Report*

(Productivity Commission, 2011). It is an insurance model, changing the funding model from government block funding to service providers to funding being managed by or for the individual. Foster et al. (2016) stated that, although created with a foundation of enabling people to live an “ordinary life” through the provision of funding for “reasonable” and “necessary” care and support, there were ambiguities and uncertainties in the implementation of the system. They conducted qualitative research of the perceptions of people with acquired disabilities, family members and service providers concerning the disability supports provided through the NDIS. The research highlighted the complexity of disability and the need for individually tailored support packages but found that the implementation of the NDIS was not delivering this adequately. Laragy, David, and Moran (2015) discussed the importance of access to information for participants to make informed life decisions but questioned if this was happening. Despite the NDIS being based on an underpinning rights-based philosophy, Goggin and Wadiwel (2014) suggest that the Australian Government promoted it as a cost saving programme. Added to these conflicting goals lies uncertainty and ambiguity around the type of support participants in the scheme can receive in relation to their romantic and sexual participation.

In summary, the perception of disability has changed over the years from a focus on the need to “fix the person’s impairment” to a more complex understanding that incorporates other aspects than the impairment. Much of this change in understanding has been brought about by activists with disabilities and has been recognised by the United Nations through the development of the ICF. The model has been used in policy, practice and research within the Disability field. The Australian government has used it as a foundation for the country’s largest social policy change in disability, the NDIS. In common with many other disability programs, the emphasis is on areas such as daily living, education and employment. The right to participate in family relationships, especially romantic and sexual relationships that are important for social participation, stated in Article 2 UNCRPD, has gained little attention in the NDIS.

3.3 Sexuality and Disability

Living with disability can increase the likelihood of having difficulties when participating in sexual activities and experiencing intimacy (Valvano et al., 2014). Sexual rights are universal rights under the Declaration of Sexual Rights (World Association for Sexual Health, 2014). Sexual expression is beneficial to one's wellbeing and health as it provides avenues to experience sexual pleasure, explore emotions and to escape from self-doubt (Gammino et al., 2016). Yet, the general public pays little or no attention to the sexual pursuits of people with disabilities, ascribing no social or economic value to such pursuits, except when they are seen as threatening socially accepted norms (Shildrick, 2009). Sexuality is a part of being human and the enjoyment of sex is innate in the character of being human, but people with disabilities encounter additional challenges in expressing their sexualities. They can face negativity concerning their sexuality from the people who are supposed to be supportive of them. They can be over-protected by parents, support workers and professionals, denied sex education in school, discouraged from engaging in adolescent activities which lead to exploring sexuality, and can find sexual health providers to be physically inaccessible (Shildrick, 2009).

However, Abramson, Boggs, and Mason (2013), interviewing 25 blind/vision impaired and sighted participants, discovered limited differences in the level of sexual enjoyment between participants whether they were blind/vision impaired or not. Citing Ray Charles, a famous musician who had lost his sight in childhood, "sex is a bitch of a motivator; it don't need no eyes" (Ritz & Charles, 2009, p. 56), they emphasised that the enjoyment of sex is innate, regardless of disability. Hurst (2003) asserted that people with disabilities have to be seen as fully human with the same rights as anyone else to reach their potential.

According to Campbell (2017) the Sexuality and Disability literature has predominantly utilised the Medical Model paradigm and frequently been based on attitudes that "are often profoundly sexist, ableist, ageist, and heteronormative" (p. 1) In her review, Campbell noted that, despite the recent rise of Sexuality and Disability research, the field is under-researched and requires greater emphasis on lived experiences, as traditionally it has had only disability as its focal point. Towards the end of the last century, sexuality and disability researchers began researching the sexual lived experience of people with disabilities with increased rigour; exploring sexual well-being and the factors inhibiting sexual expression (Campbell, 2017). One notable exception, however, as highlighted by the systematic review, is the fact that people with communication and physical disabilities are grossly underrepresented within this under-researched field.

3.3.1 The Asexual Myth

Many sexuality and disability research studies begin with the premise that wider society views people with disabilities as being asexual. Part of this view perceives disabled adults as "eternal children" in need of protection (Gammino et al., 2016, p. 158). This premise includes the prevailing notion that people who have physical disabilities, such as spinal cord injury or cerebral palsy, are unable to achieve orgasms (Gammino et al., 2016; Shildrick, 2009). As stated in the systematic review, participants within the study by Collier et al. (2006) who had complex communication needs perceived that their support workers, general practitioners and parents saw them as asexual and therefore not requiring sex education. Researchers have referred to this premise as a myth (see Collier et al., 2006; Czapla & Otrębski, 2014; Siebers, 2012).

However, Milligan and Neufeldt (2001) conducted a review of literature to identify social and empirical evidence that people with disabilities are perceived as asexual. They found strong evidence to support the existence of this misperception. Similarly, Esmail et al. (2010) conducted focus groups with members of the general public and confirmed that there is a belief that people with disabilities are asexual. Hall (2018) found that people with disabilities were posting to an online forum where they discussed their sexual desires and expressed their sexualities, providing evidence that people with disabilities can be sexual beings. East and Orchard (2013) made it clear that having a physical disability does not preclude a person from basic feelings, desires and needs.

3.3.2 It’s not normal to attempt to be normal

In reviewing the literature and reading scholars such as Shildrick, Tellier and Sieber, the researcher came to the realisation that the whole Disability field, clinical and practice, is mandated to assist people with disabilities to play a part in society and ‘fit in’ as well as possible. However, for a person with disability, the attempt to ‘fit in’ with society is an act of operating outside the norm. Having a disability often means doing things differently and this includes in their sexual activities. In Western society, the heteronormative is dominant, where disabled bodies are usually considered as not conforming, and therefore as not sexually desirable (Hall, 2018), or erotic (Shildrick, 2009). The problem is that people with disabilities generally do not follow the usual path to sexual expression, often needing alternative methods to express their sexualities and, in doing so, are often labelled deviant (Shildrick, 2009).

Ethnographic research, by Qian (2017) investigated the perceptions of caregivers of children with disabilities in a Chinese orphanage. The research found that the staff of the orphanage shared asexuality assumptions with regard to the children. The staff would strictly prohibit any sort of sexual behaviour, which at times could include homosexuality and transvestitism. The adolescents displaying behaviours considered as not conforming with acceptable norms were branded as “dangerous” or “abnormal.” The staff would explain the perceived problem behaviour as a neuroscience issue. Some adolescents, to meet their sexual needs, had developed methods to continue the sexual behaviour despite being punished and not receiving appropriate sex education. Tellier (2017) asserted that “the fact that disabled sexuality is constrained to a narrow definition of ‘appropriate’ sex, borders on unethical” (p. 490), and this was supported by Shildrick (2009) who suggested disabled people should be prepared to take a stand against the normative discourse that is so pervasive in society.

The normative discourse suggests that people with any type of disability are not viewed as potential partners as their physical appearance is not considered as sexually attractive (M. McCabe & Taleporos, 2003; T. Shakespeare, Gillespie-Sells, & Davies, 1996). The disabled body is judged against the accepted norm, seeing it as unattractive, unhealthy and dependant (T. Shakespeare et al., 1996). Hall (2018) analysed forum posts by disabled users and observed that some expressed a preference for able-bodied partners too, suggesting that some disabled people can also be repulsed by the disabled body.

The increasing usage of online technology, including social media and dating websites, has seen dating has become less formal and more casual in structure (Aumer, 2016). Research suggests that both disabled and able-bodied people considered it important for disabled people to disclose their disability from the start when using online dating. Bennett (2017), a blind PhD candidate from the human-computer interactions field, described a cooperative research project which investigated the lived experiences of people with disabilities who were using online dating sites. The research surveyed two groups, firstly people who identified as disabled, with mental health conditions as well as being deaf; and second, able-bodied people, asking them to describe recent experiences, both positive and negative, of online dating. This included their perception of the need to disclose disabilities. One of the risks involved in disclosing disability is that disabled people can expose themselves to ableist reactions which are usually negative. However, the participants reported that it was also useful to disclose disabilities for practical reasons, such as planning dates and needing to consider accessibility. The findings showed the expectations of disclosure of disability was the same online as it is face to face. Most of the participants, regardless of which group they were in, indicated that self-disclosure of disability should happen at the commencement of online interactions.

3.3.3 Development of sexuality

The adolescent and emerging adult years represent a critical time in the development of identity, sexuality and social networking (Bahner, 2018). For healthy wellbeing and relationships, the development of self-efficacy, sexual self-esteem and social networks is important for adolescents and emerging adults (Wiegerink et al., 2012). From three groups of school children, typically developing children, children with physical disabilities and children with communication and physical disabilities, it was revealed that the latter group of school children had a smaller social network than the two other groups (Raghavendra, Olsson, Sampson, McInerney, & Connell, 2012). With small social networks, people with physical and communication disabilities often experience loneliness and have limited opportunities to socialise (Balandin, Berg, & Waller, 2006; Cooper, Balandin, & Trembath, 2009; Dew, Llewellyn, & Balandin, 2014). Despite this, the men who had cerebral palsy in Shuttleworth’s research (2000a) had the self-confidence to use their own strategies, employing the difference that their disabilities gave them, that includes making potential partners comfortable with their speech and physical disability.

It is important to distinguish between the additional difficulties, in terms of support around sexuality and developing relationships, that are needed for people with acquired disabilities as opposed to people with congenital disabilities. For adults with an acquired disability, treatment focuses on rehabilitation or adapting to the new life circumstances. This includes changes to sexuality, as they may already have formed relationships and had some sexual experience. On the other hand, a developmental approach is more suitable for people with congenital disabilities, for example exploring sexuality and intimate relationships from a younger age (Shikako-Thomas, Shevell, et al., 2013; Wiegerink, 2010). This is vital, as emerging adults with cerebral palsy have additional factors to contend with concerning the management of their body, such as discovering their physical limitations, finding suitable sex positions and movement, which includes having the confidence to raise these issues with their partners (Shikako-Thomas, Bogossian, et al., 2013; Wiegerink et al., 2011). In addition, the importance of allowing and encouraging children with physical disabilities to gain privacy, seek intimacy and to develop relationships with their peers has been acknowledged, as they face greater barriers in achieving these than their peers without disability (Shikako-Thomas, Shevell, et al., 2013).

3.3.4 Support workers and assisted sex

People with severe disabilities are highly reliant on agencies providing support, and this includes support for sexual activities (Shildrick, 2009; Siebers, 2012). The type of support and funding available for people with disabilities can vary between jurisdictions (Hall, 2018). The independent living movement of the 1960s brought in the role of the care attendant (Danforth, 2018), which this thesis refers to as the support worker, to provide personal care within people's homes. However, like much of the disability sector, assistance with sexual activities is neither specified nor a high priority (Bahner, 2015). Siebers (2012) asserts that the policies and culture of supported accommodation settings, for groups of residents with disabilities, are notorious for actively limiting the opportunities for their clients to develop romantic or sexual relationships. People whose personal care is provided by support workers have additional issues to contend with in regard to developing their relationships. In particular, the need for assistance to engage in sexual activities often involves the need to negotiate with individual workers regarding the type of assistance they are willing to give. This need to negotiate can introduce other power issues for both parties, as they will be acting outside of official agency policies (Shildrick, 2009).

Governments around the world have provided support for various forms of facilitated sex services to assist people with disabilities who require assistance expressing their sexuality. The introduction of such services has been controversial and, as it is relatively new, there is little literature on the topic. Mannino, Giunta, and La Fiura (2017) reviewed and discussed the creation of a new professional role called "sexual assistant" which has been given legal status in European countries such as Germany, Denmark, the Netherlands and Spain. A sex assistant is defined as any person of either sex and of any sexual orientation who has formal training in sex facilitation and who assists people who have disabilities in extensive sexual activities (Gammino et al., 2016). Recent literature has mentioned numerous organisations globally, including *Touching Base*[3] in Australia and *The Outsiders Club*[4] in the United Kingdom, who support and advocate for the rights of people with disabilities to have access to assistance to participate in sexual relationships and activities (Campbell, 2017).

Swedish research, using face-to-face interviews and an online forum, investigated the lived experience of sexuality for people with physical disabilities who used support workers' services (Bahner 2012). The findings revealed that participants not only had to manage the relationships with their support workers but also to navigate the law, which at times can inhibit the types of support available. Participants reported the difficulty they faced in finding support workers trained to provide assistance in sexual activities. The researcher stated that

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[3] Touching Base Incorporated
Postal address: PO Box 523 NEWTOWN NSW 2042 Australia
Website: www.touchingbase.org

[4] The Outsiders Club
Postal address: WestEnd, Redwood Farm, Barrow Gurney, Avon, BS48 3RE, United Kingdom
Website: www.outsiders.org.uk

sexual facilitation is “not only an individual problem but also a political issue regarding disabled people’s sexual and human rights” (p. 788). In Japan, a service called *White Hands*[5] made available training to registered nurses “to prevent ‘sexual dysfunction’ and ‘help to ejaculate’ men with physical disabilities” (Gammino et al., 2016, p. 158). The non-profit service was originally set up in 2008 by Shingo Sakatsume, a sociology graduate from the University of Tokyo. Despite encountering widespread criticism and attention from the police, he has managed to keep the service continuing (Osaki, 2012).

In Australia, the practice of sexual assistance for people with disabilities was explored in the documentary film, *Scarlet Road* featuring Rachel Wotton (Fiske & Scott, 2011). As part of her Masters degree, Wotton (2016), researched the barriers and facilitators faced by people with disabilities in accessing and using sex workers. She conducted a survey that attracted 65 respondents who identified as sex workers providing sexual services to clients with disabilities in New South Wales, Australia. Unlike most other Australian states and territories, sex work has been decriminalised in New South Wales. The findings showed that decriminalisation made it easier for the assistants of people with complex communication needs to communicate their client’s desires and requirements to the sex workers, as there was less fear of legal consequences. However, people supporting the clients, such as friends and family, remained reluctant to assist them to access these types of sex services, despite the decriminalisation. The sex workers reported instances where they were not informed that their client used a communication board, which made their interactions more difficult, so the researcher recommended training for the sex workers and support workers in methods of facilitating communication (Wotton, 2016). The literature on facilitated sex and sex workers is sparse, yet it highlights significant interpersonal, policy and legal issues which need to be

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[5] White Hands Incorporated
Postal address: Japan Niigata Prefecture, Niigata City west district Matsumidai 8-69
Website: www.whitehands.jp/e.html

addressed to enable people with disabilities to express their sexuality in a safe and enjoyable environment.

3.3.5 Power of the state over private life

Although, sexuality is seen as a private matter, the state has a high degree of power over the sexuality of people with disabilities. Foucault, a French philosopher and social theorist, did not comment directly on disability, yet, according to Shildrick (2009), his work is useful in exposing the motivation of governments and their methods of maintaining control of citizens. Shildrick (2009) claimed that Foucault's analysis provided a framework for transcending the predominant models of disability. Applying that analysis, she argued that although sexualities and practices are regarded as private matters, the State regulated them highly with regard to which relationships, locations, and activities were acceptable and at what age. The disabled body's need for paid intervention—such as, personal care—brings with it an increase of surveillance and regulation, rendering the sexuality of people with disabilities a public issue. There is a suggestion that any benefits from changes to social policy could increase tensions associated with this issue. Shildrick (2009) theorised that there is a tension between public perceptions of tax-payers and recipients of the funding, as potential non-essentials for living are regarded as private rather than government responsibilities.

Since the commencement of the NDIS there has been a public debate as to whether the scheme should fund the services of sex workers (see: Bita, 2017; M. King, 2016; Yau, 2013). Matthew Yau (2013), a sex therapist, argued that all have the need to be loved and experience intimacy, having a disability or not, and argued that sexual service, sex therapy and sex education should be able to be acquired through government funding. The author pointed to the laws in Scandinavian countries which have strong human rights elements, such as in Denmark where citizens with disabilities can use government funding to pay for a sex worker once a month. Sex services available for people with disabilities are discussed in greater detail later in this review.

For people living in a supported accommodation setting or independently with support workers providing personal care, which are funded most by public funding, there are additional challenges in regard to developing their relationships. Shildrick (2009) asserted that the general public is accepting of personal care provided in private and behind closed doors. By contrast, although sexual wellbeing is vital, it is regarded as a luxury and therefore, not warranting taxpayer support (Shildrick, 2009). The sexuality needs of people with disabilities and the workplace safety of support workers must coexist. Places which are usually private, and intimate, become public once they become workplaces for support workers. Therefore, the activity must align with workplace safety regulations and these take preference over the sexuality and sexual needs of the client (Shildrick, 2009). As she reports, people often have to navigate the system in order to express their sexuality and being amorous within a workplace is not usually encouraged. For the participants of research undertaken by Browne and Russell (2005), it was important that their support providers had appropriate policies and procedures that catered for their sexual support needs, allowing workers to assist, thus removing the grey area that often exists. Legally supported, through policies and correct assistance being available to them, disabled people could be more adventurous in expressing their diversified sexualities (Campbell, 2017).

3.3.6 Sex and Relationship Education

It is well documented that many young people with disabilities do not receive adequate sexual and relationship education (Bahner, 2018; Hall, 2018; Howland & Rintala, 2001; Murphy, Molnar, & Lankasky, 2000; Shuttleworth, 2000b). Unlike their able-bodied peers, young people with a disability have limited opportunities to talk with their peers and explore such concepts (East and Orchard, 2013). This is especially so for those with complex communication needs who, as a result, often rely on support staff for this dialogue (K. Anderson et al., 2011; Collier et al., 2006). In particular, people with congenital disabilities often miss out on required education surrounding disability and sexuality, which impacts on their sexual experience (Shikako-Thomas, Bogossian, et al., 2013; Wiegerink et al., 2011). Collier et al. (2006) suggested parents tend to not perceive sex education as important for their disabled children, being misinformed by "the myths perpetuated by a society embedded in a history of oppression for people with disabilities—that people with disabilities are asexual and do not need sexuality education" (p. 70).

People with disabilities, especially youth, often lack adequate access to sex education and that which they do access is usually of a lower quality than their able-bodied peers can access (East & Orchard, 2013). However, there is growing recognition that people with disabilities need additional sex education. Having physical disabilities, "does not necessarily affect one's basic physiological and sexual drives or one's desire for love, intimacy, and affection" (East & Orchard, 2013 p. 336). Their Canadian-based research identified that partners, support workers, teachers and other professionals assume that people with disabilities are asexual and the young would be at risk if they had sexual knowledge. East and Orchard (2013) also pointed out that existing research in sexuality and sex education was lacking or outdated and focused on sex education for people with intellectual disabilities and protecting them from exploitation and abuse. These researchers found little research regarding the sexuality and sexual needs of young people with physical disabilities, without cognitive disabilities.

Bahner (2018) evaluated a sexuality and relationship education program in Sweden through interviews and focus groups with students with mobility disabilities. The author proposed that introducing disability practice into education would not only make it more inclusive, but also provide a broader benefit for able-bodied students. The findings also suggested that the students required, in addition to their mainstream education, instruction pertaining to their disability and how it could impact on their sexual activities. This could include managing ableist attitudes of others (Bahner, 2018). Hall (2018) echoed these suggestions, as his analysis of posts on an online forum for people with disabilities (in a thread of posts on sex positions in relation to their disabilities), identified a need for information on the positional options that could be appropriate for them, given their disability. It is interesting that two participants in Bahner (2018) picked up on the general concept of Queer/Crip Theory, suggesting that the content of the Sexuality and Relationship Education they received was mostly from the heterosexual rather than the LBGTIQ+ perspective, and that providing more information about the marginalised group, in this case the LGBTI community, could increase their understanding of sexuality.

Sex education has been found to be important and needing to start in early school years. Fader Wilkenfeld and Ballan (2011) interviewed five teachers of school age students and five instructors of adults on their perceptions of the sexual expression and activities of adults with severe developmental disabilities. An important issue the authors identified was the ability to give consent reliably and they acknowledged the fine line facing staff and guardians. These people have a duty of care to protect individuals, yet, on the other hand, must uphold the rights of the individual to sexual expression. However, most saw their role as being to teach sex education that is aligned with mainstream education, inferring that extra education was up to family, social workers and personal support providers. When discussing topics recommended for inclusion in sex education, they were concerned with protection rather that enjoyment. Pregnancy, for example, was viewed as a negative outcome for the person with a disability. The research found a positive attitude among professionals towards people with disabilities having the right to express their sexualities. The professionals acknowledged that having accessible sex education is important and it needs to be available in alternative formats to suit students' cognitive and physical abilities (Fader, et al., 2011).

3.4 Sexuality and people with complex communication needs

The systematic review identified that there was a paucity of knowledge and understanding of people with complex communication needs in developing romantic and sexual relationships in the AAC field, and the Sexuality and Disability field. In recent decades, the focus has progressed from the physical use of AAC technology, to incorporate the cognitive and social sciences (Alant et al., 2006). The romantic and sexual relationship literature has mostly concentrated on negative aspects of relationships, such as pathological issues and sexual abuse (Jonason & Balzarini, 2016). Similarly, the AAC literature has had more of an emphasis on prevention of abuse rather than sexual participation (See: Collier et al., 2006). The systematic review identified a few studies which called for improved access to sexual health services and to counselling on issues such as relationships and sexuality. It identified a lack of significant representation of people with physical and communication disabilities within the disability and sexuality literature. It called for future research into the lived experience of people with communication and physical disabilities in developing romantic or sexual relationships (Sellwood et al., 2017).

Along with being able to manage their daily tasks, health care and support workers, most people with complex communication needs aspire to assume socially-valued roles, not only as students, labourers, business leaders or academics, but as sexual beings and lovers as well (Bryen, 2008). In increasingly achieving these roles in society (Blackstone et al., 2007; Collier et al., 2010; McNaughton & Bryen, 2007), it is vital for individuals to have communication modes and skills to enable them to share with others and to foster relationships (Collier et al., 2010). However, Hemsley (2018) reported that in Australia, AAC technology was still not available to all people who might benefit, although there have been improvements in its provision. Research has shown that communication difficulties have raised barriers which reduce the capacity of individuals with complex communication needs to participate in society (Bryen, 2008; Deruyter, McNaughton, Caves, Bryen, & Williams, 2007; McNaughton & Bryen, 2007; McNaughton & Light, 2015).

3.4.1 Social Networks

To build social relationships, people need to have the ability to interact with others, to exchange ideas and feelings (Collier et al., 2010). Disability literature has reported that physically inaccessible locations limit social opportunities for people with disabilities, including in education, employment, leisure facilities, and thus limit their ability to form social relationships (Campbell, 2017). Because of their inability to communicate as fluently as is socially acceptable, people with complex communication needs frequently feel overlooked and not valued as equals (Paterson & Hughes, 1999). AAC literature has recognised that people with complex communication needs often have limited social networks and are socially isolated, making it difficult to meet new people and make friends (Ballin & Balandin, 2007; Cooper et al., 2009; Dew et al., 2014). Other barriers people with complex communication needs encounter in socialising include people lacking the patience to give them the time to communicate, people ignoring them and the noise levels in public venues where people usually meet to socialise (Ballin & Balandin, 2007). These barriers further limit the romantic and sexual opportunities for people with complex communication needs.

To improve the social opportunities of people with complex communication needs, specific interventions are needed and, as discussed, AAC research has shown that these need to start at an early age (Balandin, 2011; Beukelman & Mirenda, 2013). AAC interventions can be unaided (e.g., speech or gestures), aided (e.g., communication books and AAC devices) or multi-modal, or combinations of strategies (Beukelman & Mirenda, 2013).

However, there is little research on effective methods of supporting adolescents and emerging adults in sexuality and relationship education, nor on providing appropriate vocabulary to express identities.

3.4.2 Expressing identity

In a BBC Three video by G. King (2015), Lewis, like any typical teenage male, considered it important to be able to express his identity through his voice in order to participate in adolescent relationships. He was from Newcastle, UK, and was living with cerebral palsy. In the video, Lewis was shown talking to several people using gestures and a speech generating device, conveying his dislike of the electronic voice in his device and his desire for another voice. When asked what voice was currently on it, he replied, “It is shit (sic) one! […] English / USA but I don't get all the girls with it. Basically, you don't get none of the girls with this American accent.” As Lewis was contributing to the conversation, using gestures and his AAC device to communicate key words and concepts, his classmate elaborated on them to keep the conversation going. The video demonstrates how speech-generating AAC devices and co-constructed conversations can impact the ability to express identity.

Our voice identifies who we are; it portrays where we come from, and sometimes our sexuality, so having to communicate through an electronic voice that is not our own can affect how people interact with us. Stephen Hawking, a renowned theoretical physicist, used the same electronic sounding voice in all the devices he used over the years, despite the huge advancements in the quality of the electronic voice. He understood that the general public knew that voice as his and his identity was connected to that voice (Hemsley, 2018). Similarly, Lee Ridley, a disabled English stand-up comedian known as “Lost Voice Guy,” alluded to his AAC voice not matching his identity in his audition on Britain's Got Talent (2018). Within his comedy routine he articulated, “Well, I realized I'd never be able to talk again I was speechless. I have lived in Newcastle all my life, yes, but for some reason I still hadn't picked up the accent.” Yet, the Lost Voice Guy expressed his identity through skilfully using a speech-generated device (Britain's Got Talent, 2018).

People with complex communication needs, who use speech-generating devices, are disadvantaged in forming social relationships and expressing their identities. Wickenden (2011) conducted qualitative, predominantly ethnographic, research with adolescents to investigate expression of identity while needing an electronic voice. The findings demonstrate that people who use AAC usually have multiple modes of communication and are skilled at choosing which method to use in different situations and with different communication partners, despite physical impairments and the technical restraints of available technology. Using one of the concepts of Bourdieu (1986), the competition of social capital within social fields, the author suggested that people choose the communication mode that they perceive will provide the greatest return. “However, it is often overlooked that despite not having the individuality of a physiological voice, AAC users can and do express their identities through their unique way of using their AAC” (Wickenden, 2011, p. 6).

Another method of expressing identity and sexuality has been explored through a short video called “Bummunicator” (Sellwood, 2015), which was presented at the research symposium of the 2016 International Society of Augmentative and Alternative Communication conference in Toronto. It was created to highlight the importance of being able to express one’s identity and sexuality when in a wheelchair. In the summary of the two-day session, the convenors highlighted the importance of AAC research to include elements such as identity and sexual expression beyond voice. They stated, “Yet far from being just a joke, Bummunicator invited reflection on issues of disability, sexuality, and the right to define one’s own borders of taste and conduct. It represented a notion of voice beyond speech, to include body language, clothing, and identity” (Pullin, Treviranus, Patel, & Higginbotham, 2017, p. 146). People with complex communication needs have to become skilled in using alternative communication to express their identities and to form desired relationships.

3.4.3 Vocabulary accessibility

Whether people use AAC that is unaided or aided, the vocabulary they have available also has a significant impact on their ability to express themselves, and thus to meet and form relationships with potential partners. Wickenden (2011) discussed their dependence on others for their vocabulary and asserted that efficient access to appropriate vocabulary that supports communication is vital. For adolescents, this could limit their interactions with their peers, which often required them to use some immature language. If the AAC field is serious about assisting people to participate in society, it must allow people to employ the vocabulary of their choice and of their social environment, including within groups of potential romantic or sexual partners. Nevertheless, Bryen (2008) revealed nearly half of the words identified as needed for participation in sexuality, sex, and intimate relationships, were not available within three predominant commercial AAC symbol sets. Although, people with complex communication needs can be highly skilled communicators, using their AAC systems enabling them to express themselves and enter into relationships (Wickenden, 2011), arguably, some of the largest barriers they encounter are AAC practitioners and manufacturers limiting the vocabulary and design features of AAC devices.

3.5 Conclusion

All human beings are granted the right to have romantic or sexual relationships (World Association for Sexual Health, 2014; United Nations, 2006). Literature has reported that people with complex communication needs participate in these sorts of relationships (K. Anderson, Balandin, & Clendon, 2011; Bryen, 2008; Collier et al., 2006; Murphy et al., 2000; Shuttleworth, 2000a), However, people with complex communication needs are under-represented in the disability and sexuality literature (Campbell, 2017). The little AAC literature that exists regarding sexual activity has had an emphasis on protection rather than active participation (Sellwood et al., 2017). To date, little is known of the lived experiences or the barriers and facilitators encountered by people with complex communication needs in developing romantic and sexual relationships.

Research is needed to inform and improve future evidence-based interventions aimed at advancing the social and intimate participation of people with complex communication needs. Their lived experiences should be explored to gain a deeper understanding and knowledge of their experiences in developing romantic and sexual relationships. In gaining this understanding, the types of barriers and facilitators they encounter can be identified, contributing to the evidence base for interventions that support them in their relationships. Finally, the findings of this research could be used to inform the development of AAC practices to respond to the sexual intimacy needs of people with complex communication needs.

3.6 Research Aims and Questions

The aims of this research were (a) to investigate the lived experiences of people with complex communication needs in developing romantic or sexual relationships, and (b) to identify barriers and facilitators they encounter in these pursuits. The research questions were as follows:

- What are the lived experiences of people with complex communication needs in developing romantic or sexual relationships?
- What are the barriers and facilitators to developing romantic or sexual relationships for people with complex communication needs?

4 Theoretical Framework

This qualitative research used a phenomenological approach, exploring the lived experiences of the participants (Creswell, 2012). To understand the lived experiences of people with complex communication needs, a theoretical framework was developed, drawing on the concept of ableism, critical hermeneutics, Feminist Standpoint Theory and the International Classification of Functioning, Disability and Health (ICF) model. This framework was utilised in data collection and analysis.

Kent-Walsh & Binger (2018) stated that qualitative research was often misunderstood as an invalid methodology in the AAC field, but that in recent years the field has acknowledged it as valuable for providing evidence-based support to the field. In the special edition of the Augmentative and Alternative Communication Journal dedicated to qualitative research within the field, Balandin and Goldbart (2011) highlighted that qualitative research is beneficial to investigate social phenomena which are new or have had little research. Each of the four elements of the theoretical framework will be discussed below.

4.1 Ableism: Discriminatory Attitudes

The Sexuality and Disability field has predominantly taken an intersectional approach in investigating the discrimination people with disabilities encounter, drawing on the disability studies, queer theory and feminism fields (Campbell, 2017). Within Disability Studies, there are numerous terms to refer to the discrimination people with disabilities encounter within society (Bahner, 2018). McRuer (2010) uses the phrase, *compulsory able-bodiedness*. Campbell (2017) uses the term *ableism*, which this thesis has adopted. It is a set of negative belief or assumption that people with disabilities are inferior, broken and needs to be fixed (Campbell, 2017). Most of the main reasons people with disabilities face denial of sexual expression and pleasure can be attributed to ableist attitudes, such as perceptions of being childlike, requiring protection, being physically unable to have orgasms or not being sexually attractive (Gammino et al., 2016). They do not only encounter ableism from the general population, but also from their families, friends, support workers, and medical professionals (Campbell, 2017). As ableism is so prevalent in society, children growing up immersed in it can internalise some of these negative beliefs and assumptions concerning their self-worth, appearance, sexuality and ability (Campbell, 2017; Shildrick, 2009).

As previously mentioned, literature in the AAC field has reported that it is difficult for people with complex communication needs to socialise and meet new people. The common reasons for this are impatience, as able-bodied people frequently do not allow time for messages to be generated, and people with complex communication needs are socially excluded (Ballin & Balandin, 2007). All of these can be products of ableist attitudes.

People with disabilities contend with ableism, not only from the general population, but from the very people who would be expected to be supportive of them: support workers, parents and medical professionals (Campbell, 2017). The social and sexual development of adolescents and emerging adults who have disabilities can be negatively affected by limited opportunities to develop relationships that could lead to sexual experiences, a lack of adequate sex education and negative attitudes of support staff, including teachers (Bahner, 2018).

An able-bodied partner of a disabled person can also experience ableism. Goldstein and Johnson (1997) surveyed 179 newly-enrolled, able-bodied university students, and found that able-bodied partners of disabled people were negatively perceived, attracting stigma. Drawing on literature, Campbell (2017) highlighted that able-bodied partners are often viewed differently. People's perception of them is often that they are a "special person" to be with someone who has a disability or they are assumed to be their disabled partner's support worker. "Assumptions such as these uncover hidden biases that deny the reality that people with disabilities are sexual beings and display the pervasive ableism within society" (Campbell, 2017, p. 8).

With ableism so prevalent in society, as children grow up immersed in it, they can internalise some of these negative beliefs and assumptions concerning their self-worth, appearance, sexuality and ability (Campbell, 2017; Shildrick, 2009). However, many people with disabilities have developed strategies to counteract the ableism they face. For example, in Shuttleworth (2000a), a study of men with cerebral palsy seeking sexual intimacy, some of the men reported developing strategies to use their differences, their disabilities, to make it easier for new people to meet them, effectively subverting ableism. In this research, the concept of ableism has been used to analyse the interview data.

4.2 Critical hermeneutics

A critical hermeneutics approach was utilised in this research to explore the participants' lived experiences (Creswell, 2012). Phenomenology, concerned with lived experiences, attempts to uncover the commonalities of the experiences of participants in order to obtain an understanding of the phenomenon being studied. A key feature of phenomenology is an attempt to acquire a universal description of the phenomenon which is known as the *essence* of the experience. A particular phenomenon is selected to be studied, such as losing a loved one, winning the lottery, attending a mainstream school or having a support worker provide personal care. Interviews are conducted with people who have experienced that particular phenomenon. A description of the phenomenon is formulated from the collected perspectives of participants. This description captures *what* and *how* they have experienced the phenomenon (Creswell, 2012).

Fochtman (2008) provides a history of phenomenology dating back to the Greek philosophers Plato, Socrates, and Aristotle. The development of Cartesian duality, a systematic division of the mind from body constructed by French philosopher and mathematician Rene Descartes (1596-1650), stood in contrast to the work of many of the earlier philosophers. Phenomenology started to emerge following the development of Cartesian thought. The development was not a linear process, taking numerous interrelated forms. Edmund Husserl (1859-1938), a German mathematician later turned philosopher, proposed a phenomenology that attempted "to return to 'taken for granted' experiences and to re-examine them in an intentional manner that brings to light the essence (meaning) of human experience" (Fochtman, 2008, p. 186). The process included a practice called *bracketing*, requiring the researcher to separate their previous knowledge, beliefs, assumptions and biases relating to the phenomena being examined. Maurice Merleau-Ponty (1906-1961), a French phenomenological philosopher, was strongly influenced by Husserl yet he argued that Husserl's reduction phenomenology was not realistically possible. For Merleau-Ponty, it is our previous knowledge and understanding of the world that assist in analysing experiences. Similarly, Martin Heidegger (1889-1976), disregarded Husserl's constructionist phenomenology and focused on the experiences of people in order to better understand phenomena.

According to Lopez and Willis (2004), descriptive phenomenology aims to describe a phenomenon whereas interpretive phenomenology, also known as hermeneutic phenomenology, builds on this to attempt to give meaning to a phenomenon. To gain understanding of the phenomenon, hermeneutic phenomenology also enables the researcher to draw on their prior experience and knowledge and utilise theoretical frameworks to analyse the background, culture and social environment.

"To truly understand another human being, we must investigate how he or she perceives an experience." (Fochtman, 2008, p. 185). This was a shift from the post-positivist worldview perspective with a focus on identification and rectification of problems, as hermeneutics is focused on exploration of the phenomenon to achieve deeper understanding

(VanLeeuwen, Guo-Brennan, & Weeks, 2017). The term *hermeneutics* refers to a philosophy and methodology that attempts to understand a phenomenon from the perceptions of the research participants by obtaining the point of view of the people experiencing the phenomenon. In understanding the entirety of a phenomenon, its individual parts must be understood and vice versa. This is known as the *Hermeneutics circle*: the whole is connected to the individual parts. One cannot be understood fully without also understanding the other (Fochtman, 2008). Fochtman (2008) suggests the circle could also be the constant interconnection between understanding the self and the world.

Critical hermeneutics is an extension of the interpretive tradition in phenomenology with a focus on the marginalised and oppressed. In contrast to pure phenomenology which aims to objectively observe a phenomenon without any pre-conceived notions, critical hermeneutics allows the researcher to utilise or develop theoretical frameworks designed to critically analyse the phenomenon. It attempts to provide a deeper understanding of the cultural norms and power struggles people face, and by giving voice to the marginalised, becomes a type of emancipatory research. Although the most common methods used in phenomenology are in-depth interviews to explore what was experienced and how, other methods include analysing written text (Lopez & Willis, 2004). The role of the researcher is changed by the use of a critical hermeneutics approach, giving more importance to the voices of participants, and de-emphasising the expertise of the researcher (VanLeeuwen et al., 2017).

This research investigated the phenomenon of people with complex communication needs, who are often on the margins of society, even within the disability sector, developing romantic and sexual relationships. Critical hermeneutics enabled me to interview people who experienced the phenomenon, empowering them to share their stories and insights to generate new knowledge which could assist to inform practice and policies. Because of the communication difficulties of the participants, this approach was important as it allowed me to use my own background knowledge and insights to enrich understanding of the participants' contributions. However, as I am also a member of the cohort being studied (i.e., an individual with complex communication needs who uses AAC), it was important to recognise and acknowledge the contribution of my own understanding of the culture and power structures.

4.3 Feminist Standpoint Theory

Once the research project was designed and data collection was being undertaken using a critical hermeneutics approach, it became apparent through further reading and discussions with other academics, that the research would benefit from drawing on Feminist Standpoint Theory. This has a similar objective to a critical hermeneutics approach, in being focused on augmenting the voices of people in minority groups and acknowledging the value that the researcher's own experiences and knowledge can contribute to understanding and to analysing the data.

Daukas (2017) asserts that Feminist philosophy is set apart from conventional philosophy by its aim to gain understanding of a phenomenon, to investigate ways to overcome injustice and social power inequities in order to bring positive social change. This involves gaining a full understanding of the issues occurring, using philosophical reflection to understand social power and injustice in a society (Daukas, 2017). By its nature, Feminist philosophy is political as it seeks to change society. In the 1960s and 70s, the beginnings of the Feminist movement, the discourse was predominantly focused on the lived experiences of women who were white, middle class, able-bodied, educated and heterosexual. Since the 1980s, other female thinkers started questioning the understanding and concept of feminism, suggesting that while it claimed to be liberating, it was oppressive to other women. Lesbians and black writers highlighted the need to focus not solely on gender, but also on other factors that have the effect of marginalisation. When oppression occurs, it is likely to include other elements such as sexuality, race, class, and ability. The concept of intersectionality introduced the idea that multiple elements can have an impact on one's lived experiences of a phenomenon. For example, the experiences of a white, able-bodied woman working in an office would be different from those of a black woman with a disability. Two office workers would be likely to encounter different forms of discrimination, racism, sexism and ableism. Factors other than gender must be addressed to attempt to understand social power structures and injustice, in order to bring about liberation (Daukas, 2017).

Research investigating people who are marginalised by society should not be about marginalised people but should be conducted for them or on their behalf (Vaditya, 2018). One of the objectives of this kind of research is to disturb what constitutes knowledge creation, knowledge production and the accessibility of knowledge. It recognises that situational knowledge has a legitimate place in knowledge creation, and also attempts to depart from the Eurocentric epistemological bias to knowledge which perpetuates the status of the dominant and silences the marginalised (Vaditya, 2018). Haraway (1988) was the first to use the concept of the *situated knower,* acknowledging that the knower is embedded in the social structure. The position of the knower in relation to the phenomenon being studied, can influence their understanding and knowledge of the social relationships.

> *If knowers' places in a social hierarchy affect their knowing, then if a powerful and privileged social group historically dominates a given field of knowledge without critical self-awareness, knowledge in that field is likely to be excessively partial and distorted. Furthermore, it is likely to represent how things appear from a position of social privilege to be how things simply are. According to feminist philosophers of science, that is true of much work in Western science (Daukas, 2017, p. 67).*

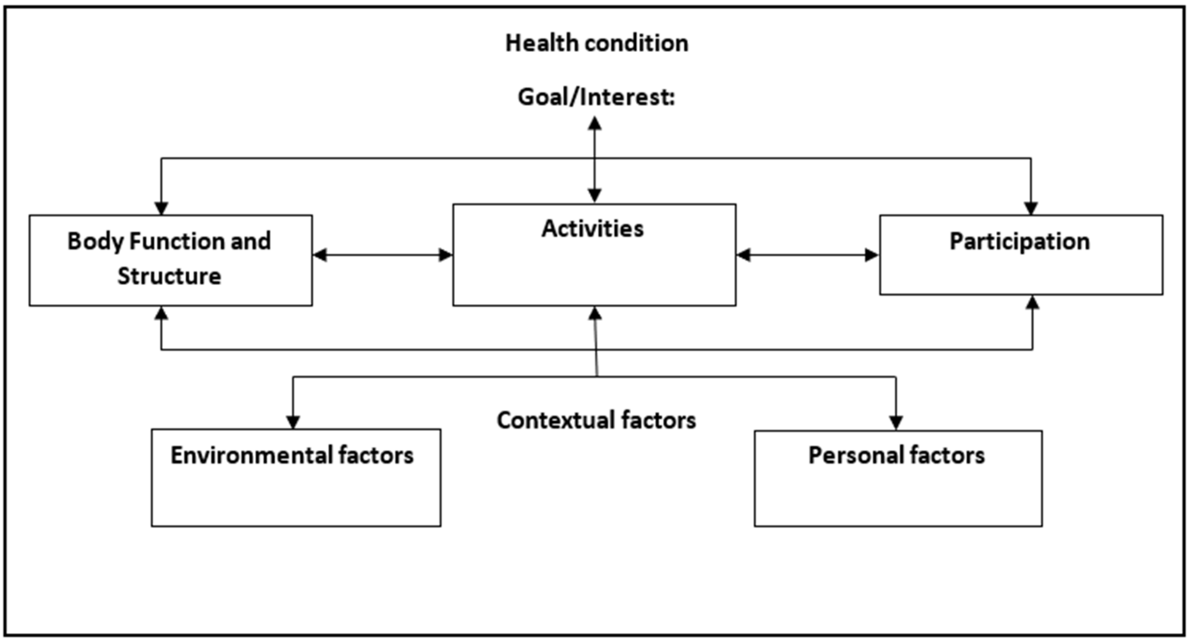
Hartsock (1983) developed Feminist Standpoint Theory based on the Marxist concept of the labourer. Marx asserted labourers have more knowledge of society, economics and materials than their capitalist employers because of their subordinate positions (Hartsock, 1983). The dominant people, employers, do not have access to this additional knowledge. From a researcher's point of view, gaining insight from the people within the social structures assists in understanding the phenomenon which is being researched. It also helps highlight the power structures that maintain the dominant/subordinate status. Collins (1986) introduced the concept of *the outsider within,* suggesting the researcher who identifies as a member of the researched cohort has *double vision.* The researcher understands their role as defined by the dominant academia but also has insights and knowledge which come only from within the cohort. This knowledge and their social status within the cohort enables them to ask questions and have access to perspectives that outsider researchers would not understand.

Using a critical hermeneutics approach together with Feminist Standpoint Theory provides the optimal way to gain an understanding of the lived experience of people with complex communication needs in developing intimate relationships. Adopting Collins (1986) *the outsider within* concept allows me, as the researcher, to draw on my personal knowledge and experience as both a researcher and a member of the cohort to investigate the phenomenon in ways that may not be available to an able-bodied researcher.

4.4 ICF model

As discussed in Section 3.2.1.4, the ICF model goes further than the medical and social models, the two predominant models of disability, by taking into account that "disability is characterized as the outcome of a complex relationship between an individual's health condition and personal factors, and of the external factors in the individual's environment, thus highlighting the interactive nature of the model" (Raghavendra et al., 2007, p.352). The ICF model is increasingly being used within the field of AAC in clinical and research practice (Fried-Oken & Granlund, 2012). In acknowledging the interactions between body structure, function and activity, the model assists AAC practitioners and researchers to consider both personal factors and environmental factors. The ICF provides a framework for designing interventions and research, to contribute to improved participation outcomes for AAC users by emphasising and enhancing their capabilities within their various environments (Light & McNaughton, 2015). The ICF model shows the five main domains (see Figure *4.1*).

Figure 4.1 International Classification of Functioning, Disability and Health model



One shortcoming of the ICF is that while it acknowledges people’s personal attributes as factors in their experience of disability, it does not identify them as barriers or facilitators to participation, as it considers doing so would be *blaming the victim* for their flaws (Leonardi et al., 2016; Simeonsson et al., 2014). However, the ICF does provide an inclusive framework within which to research social participation of people with disabilities as it acknowledges that disability is complex. Its focus on participation in society acknowledges that both self and the environment play critical roles. This research used the ICF to develop the interview questions, to explore the interviewees’ experiences, analyse the data, develop themes and derive meanings.

4.5 Conclusion

These four elements—critical hermeneutics, Feminist Standpoint Theory, the notion of Ableism and the ICF model—provided a strong foundation within the design of this research, data collection and data analysis. Both a critical hermeneutics approach and Standpoint Theory encapsulated a method that empowered the participants to share their experiences and identified barriers and facilitators encountered by them. The notion of ableism provided a conceptual understanding of the types of discrimination people with disabilities face, while the ICF model emphasised the complex nature of disability by setting up a structure within which to explore it. This theoretical framework provided a construct to understand the experiences of people with complex communication needs in developing romantic and sexual relationships.

5 Methodology

This chapter provides a description of the methodology and procedures used to investigate the lived experiences of people with complex communication needs in developing romantic or sexual relationships. The chapter first presents the rationale for the qualitative approach utilised, then discusses the methods including the data collection and analysis processes.

To ascertain the perspectives of the participants, a critical hermeneutics approach and Feminist Standpoint Theory were employed. The design of the study has drawn on the researcher's experience as an *insider* (Haraway, 1988) to the cohort of people with complex communication needs being the researched, and thus brings a unique perspective to conventional methodology and methods described in this chapter. In presenting the study design and methods, certain features of the design which needed additional consideration are also discussed, given the unique physical and communication challenges which had to be addressed because both the researcher and the participants had complex communication needs.

The semi-structured interviews were designed using the International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2001). Interview transcripts were analysed using QSR International's NVivo 11 qualitative data analysis software to identify common themes. Human Research Ethics approval was obtained from the Social and Behavioural Research Ethics Committee of Flinders University (Project Number 7029) prior to the commencement of the research (see Appendix 1).

5.1 Study Design

As previously presented in the Theoretical Framework chapter, to understand the development of romantic or sexual relationships among people with complex communication needs, it is important to comprehend their experiences. Hence, qualitative research, using a phenomenological approach exploring the lived experience was utilised (Creswell, 2012). According to Lopez and Willis (2004), descriptive phenomenology aims to describe a phenomenon whereas interpretive phenomenology, also known as hermeneutic phenomenology, builds on this to attempt to describe and give meaning to a phenomenon. Critical hermeneutics is an extension of the interpretive tradition in phenomenology with a focus on the marginalised and oppressed. It attempts to provide a deeper understanding of the cultural norms and power people face and to give voice to the marginalised, therefore becoming a kind of emancipating research. Although the most common methods used in phenomenology are in-depth interviews to explore what was experienced and how, there are other methods available such as analysing written text (Lopez & Willis, 2004). Using critical hermeneutics, the researcher was able to incorporate his prior experience and knowledge, and to introduce cultural, social and environmental explanations and theoretical frameworks into the research.

5.2 Additional considerations: Communication difficulties of the participants and researcher

In research involving participants using AAC, there are additional methodological issues to consider, which are usually taken for granted by other researchers. This is especially critical for this research as both the researcher and the participants have physical and communication disabilities. The researcher has previously been a participant in research interviews, both face-to-face and by email, and has found that those conducted by email have taken days to complete, and while the face-to-face interviews could be physically exhausting, they were more interactive and able to yield richer data. These methods might seem logical considering the participants' communication disabilities, as they could be accessible online, allowing participants to respond at their own pace and timeframe.

However, people with complex communication needs face multiple barriers to participating in research, the first being that many have low literacy levels, inability to access the internet independently and expend considerable physical effort and time in typing (Raghavendra, Newman, Grace, & Wood, 2013). If a participant uses an assistant to support the preparation of responses, the authenticity of these responses becomes an issue as it is difficult to determine whether the response reflects the participant's perspective or has been influenced by the assistant (Wickenden, 2011). For this project, it was also deemed that monitoring participants' emotional responses was important but impossible to achieve through online forums or email interviews. In considering these factors, it was decided to use face to face interviews based on the advantages discussed below.

Face to face interviews allow the interviewee, the person with complex communication needs, to choose the communication mode they perceive as most efficient for them to respond to interview questions. This includes using their own speech, AAC strategies, gestures, body language and facial expressions. Face to face interviews enable the interviewer to determine the authenticity of the participants' contribution, to provide immediate responses to participants' nuances and emotional states, and can be more time efficient and produce richer data. Despite these benefits, the quality and quantity of data collection can be limited, due to the extra time and effort required because of participants' communication difficulties and physical disabilities.

Related to this limitation, the choice of face to face interviews as a method requires further considerations to be addressed. Firstly, based on the past research experience of the researcher and his supervisors, it was acknowledged that attracting participants locally or even nationally would be difficult due to the cohort being small in number. Conducting face to face interviews locally and interstate would have been achievable through considerable organisation, however, it was recognised that the size of the cohort could be increased by recruiting internationally and using teleconferencing technology. It was confirmed that to conduct interviews internationally by this technology required local ethics approval only.

Consideration was also given to the researcher’s communication disability and the complexity this may have added to the interview process and that his insider status could have been perceived by participants as a possible threat. The option was explored of having a different person conducting the interview with the researcher as an observer. The researcher analysed the advantages and disadvantages of both approaches and on balance, believed that his insider status brought the value of the additional insights to the interviews. This, together with his communication skills would enable him to enhance his rapport with participants and encourage them to talk more freely about personal issues. A practical issue involved the difficulty of finding someone with the skills and availability to conduct the interviews at times which suited international participants. After much deliberation with his supervisors it was decided that the researcher would conduct the interviews, with academic assistants to support communication.

As discussed in the systematic review, the AAC literature concerning sexuality has been dominated by the topic of protection from sexual abuse and revealed that people with disabilities are at a higher risk of experiencing physical and sexual abuse. This risk is even higher for people with complex communication needs (Bryen, Carey, & Frantz, 2003). However, the focus of this research was on the lived experience of people with complex communication needs, not on abuse. Nevertheless, the researcher and his supervisors invested a considerable amount of time to ensure the safety of all present in the interviews, especially the participants. This included the researcher and his academic assistants having the appropriate police checks for working with vulnerable people, while the recruitment material asked potential participants, communication assistants and academic assistants to ensure that they knew where they could receive counselling services if needed.

5.3 Participants

The aim was to recruit 20 participants who had congenital physical and communication disabilities and used at least one alternative or augmentative method of communication. The target population was expanded during the recruitment to include potential participants who acquired their physical disability in their childhood. It was necessary, given the sensitive nature of the topic, for the participants to be over the age of consent and considered to be adults. In Australia, this age is 18, however this varies internationally (AgeOfConsent.net, 2015). A conservative, minimum age for participation was set at 21 years to simplify international recruitment and to increase the likelihood of participants having had adult relationships.

It was also important to allow participants to choose the communication modes that they deemed most effective to use within the interviews. It was expected that some would use communication assistants within the interviews and, in these cases, the participant needed to have the ability to confirm independently that the revoicing conveyed their intention. Accordingly, they were required to be able to provide reliable Yes/No responses independently, without assistance, and this needed to be demonstrated in the initial stages of the interview. The final criterion was to ensure that participants were able to understand the requirements of the project and therefore give informed consent. Informed consent was deemed important because of the nature of the research and the vulnerability of the cohort.

The recruitment criteria required participants to:

- be at least 21 years old
- communicate in English
- have had a physical disability since childhood
- have complex communication needs

- use at least one aided AAC method (communication board or book, speech generating device, iPad)
- provide reliable Yes/No responses independently, without assistance
- understand what they would be asked to do in this project and indicate that they would like to participate.

5.4 Recruitment

Following ethics approval, recruitment occurred between November 2015 and December 2016 using a multimodal approach. The participants' recruitment documents included the Participant Introductory Letter, Participant Information sheet and Participant Expression of Interest (see Appendix 2, 3, 4). These documents were available for printing and emailing. A version of the Expression of Interest form was developed using Lime Survey hosted on the university server. In the online version, to encourage reading of all the documents, the user had to scroll through the first two documents before proceeding to the Expression of Interest. To increase the accessibility of these online documents they were available as pdfs for downloading as well as in html format for ease of screen reading. The majority of interested parties used the online version.

The researcher assessed each of the Expressions of Interest received for eligibility and then sent an email to the respondents thanking them for their response. There were three email templates used by the researcher for those who did not meet the criteria (see Appendix 5), those whose eligibility was questionable and requiring clarification (see Appendix 6) and those who had met the criteria (see Appendix 7). Emails to eligible respondents also included, for the participant, the Introductory Letter and Information sheet, with an Interview Outline (see Appendix 8) and Consent form (Appendix 9). They also included a Consent form, Introductory Letter and Information sheet (see Appendix 10, 11,12) for a possible

Communication Assistant. The Interview Outline was provided to give participants a chance to consider participating and time to prepare their responses.

Ellis and Bochner (2006) suggest that research must be designed to be beneficial to participants. It was important to the researcher to be able to offer a reimbursement for their participation, considering the extra time and physical effort required. From his experience, and as research suggests, people with disabilities, especially people with complex communication needs, are frequently asked to be research participants but receive little acknowledgement. To honour their participation, even though it was still tokenistic, the researcher budgeted to offer the participants a shopping voucher worth $40 AUD. Initially, the choice was limited to Apple or Coles, however, to provide greater flexibility for international participants, Amazon vouchers were also offered.

5.4.1 Online recruitment

The main media used to broadcast information included online advertisements on social media sites, two AAC email listservs (electronic mail subscribe services) and the snowball email approach. The two prominent email listservs related to AAC, Australian Group on Severe Communication Impairment (AGOSCI) (see Appendix 13) and Augmentative Communication Online Users' Group (ACOLUG) (see Appendix 14), provide platforms for people with complex communication needs, family members, support staff, professionals and students who are interested in the AAC field to share ideas and information. Although these platforms discourage promotional material, including research recruitment posts, they encourage the sharing of relevant AAC information, so the researcher shared information regarding the research project without directly asking for participants. Both emails were vetted by the listserv managers before being sent to members. Following this, a personal contact of the researcher recommended Communication Matters UK be approached regarding posting the recruitment information on their forum and an email was sent (see Appendix 15).

In the development phase of the project, it was understood that a portion of the recruitment could occur by utilising the online presence of the university, so the Facebook advertisement text (see Appendix 16) and Twitter text advertisements were prepared (see Appendix 17). When the researcher approached the university, they advised that this feature did not exist, and suggested that a request be lodged to post the recruitment advertisement on the university’s "Volunteer for Research studies webpage." Only one response came from this volunteer webpage but the person did not meet the inclusion criteria.

Another method of broadcasting advertising material was a Facebook page in support of the project, set up independently by one of the researcher’s friends. The page was called *Getting Past “Let’s Just Be Good Friends.”* The friend, knowing some of the ethical implications, allowed people to “Like” and “Share” it but not enter any comments on the page (Getting Past “Let’s Just Be Good Friends," 2016). It was shared through the AAC community on Facebook generating some discussion and seeing the posts repeatedly could have encouraged some to participate. The researcher and the friend did not have direct contact with potential participants, thereby avoiding the perception of coercion. Also, the moderator of the *Just CP* Facebook page, which globally had one of the largest memberships of people with cerebral palsy (Just CP, 2016), was approached to share the recruitment information on their page. The moderator posted the recruitment information on the Facebook page at least twice over a two-week period.

The snowball email recruitment approach was used by sending an email to 21 professional contacts of the researcher (see Appendix 18), describing the research project and including the Participant Information Sheet along with the Letter of Introduction. The email requested that they pass the information on to potential participants or other interested people.

The rationale for this was that it was felt that people with complex communication needs were more likely to respond to research recruitment material if personally invited to participate. In the early stages of recruitment, to avoid any sense of coercion, the researcher and his supervisor abstained from directly approaching potential participants but felt that personal contact was a vital factor for people to participate, especially given the personal nature of the topic. More than half responded positively, advising that they would forward the email as requested.

At first it was thought that having a target of twenty participants would be achievable, given that the researcher was recruiting internationally. The researcher and his primary supervisor are known and respected within the AAC field and numerous people suggested that they would be interested in participating when the recruitment commenced. However, this anticipated interest did not result in the numbers expected. Based on previous experience in the course of his Honours degree (which involved researching the perceptions held by people with complex communication needs about telecommunications), the researcher understood that traditional research recruitment methods could prove difficult when obtaining a sample from the targeted cohort.

Six months into the recruitment phase, there had been only five expressions of interest, and from these only three were interviewed. Following a review of the project status and recruitment process, three separate actions were proposed. Considering the lower than predicted number of expressions of interest received, it was decided to revise the required number of participants from 20 to 10. Secondly, an address list was created for a direct mailout by email to disability-related organisations, but the emails were not sent as it was determined that the third course of action would be more effective. This involved seeking ethics approval for the researcher to directly approach potential participants.

5.4.2 Direct approach recruitment

A direct approach is usually considered to be undesirable due to the possibility of coercion of participants. While it seemed that there was a lot of interest in the project, known potential participants did not submit expression of interest forms. The researcher suspected that some were more comfortable responding to a personal approach, as people with complex communication needs tend to communicate mainly with other people they know and who are familiar with their communication methods. As the project was about communication barriers, using a direct approach method to reduce the barriers was deemed appropriate. Much consideration was given to the design of this direct approach method to minimise the potential for coercion and it was not implemented where there existed a possible power relationship between the two parties (for example, ex-partners of the researcher, clients or students of the primary supervisor).

The direct approach took two forms. The first involved the researcher emailing potential participants known to him personally, using direct email contact (see Appendix 19). This email informed the recipient of the research project, invited them to express an interest through the website but allowed them to choose whether or not to take part. They were also assured that there would be no repercussions if they chose not to participate. The second form was implemented when the researcher, his support worker and his primary supervisor attended the International Society of Augmentative and Alternative Communication (ISAAC) 2016 biannual conference in Canada. It was anticipated that they would meet numerous people with complex communication needs. Receiving ethics approval allowed them to approach potential participants directly and it was proposed that these methods would also be used upon returning to Australia.

This process entailed scripts being prepared for the researcher, his supervisor and assistant to use when introducing this research to potential participants (see Appendix 20). A pamphlet was prepared as a cut-down version of the Participant Information Sheet (see Appendix 21) providing the most important information and directing people to the Expression of Information site. An invitation to participate was also provided at the end of a research presentation at the conference.

5.5 Data Collection

The data collection took the form of semi-structured interviews. Interviews were conducted between February 2016 and December 2016. These were spread over a number of sessions with a maximum of three hours depending on the needs of the participant. Each session was videoed, as is common in AAC research, to ensure people's responses were accurately captured. This section will discuss the design of the interview schedule and procedures. Following this, the method of data analysis will be presented.

5.5.1 The development of Interview Schedule

The Interview Guiding Questions Schedule (see Appendix 22) was developed using the ICF framework (World Health Organization, 2013). The researcher first proposed a set of interview questions based on the literature and aims of the study. Interview questions were developed to gather background information, participants' social relationships and sexual experiences using various components of the ICF. The researcher then refined the interview schedule in consultation with his supervisors.

Two pilot interviews were conducted to test and refine the interview process and questions. The first pilot interview was conducted with a fellow PhD student who had no communication or physical disability. This enabled the schedule to be tested without the additional considerations required for the sample group. In the second pilot interview the participant had cerebral palsy and dysarthric speech. The second pilot enabled the schedule to be further tested with a person who was a member of the targeted cohort. This gave an opportunity to identify additional issues which are specific to interviewing people with complex communication needs and physical disabilities.

After each of the pilot interviews, the researcher prepared transcripts of the interviews and a list of proposed modifications to the interview schedule, which was sent to his supervisors along with links to the interview videos. Following meetings and emails with supervisors, modifications were made to the interview schedule. The supervisors also provided feedback on the researcher's interviewing style. This enabled the identification of any issues in the interview schedule and provided an opportunity to sharpen the researcher's interview skills. The pilot interview findings were not included in the data for the project.

With regards to the modifications, there were several questions deemed repetitive or be too academically worded. As a result, the interview questions were either merged, reworded or removed from the schedule. In a few cases, questions were moved to more appropriate sections of the schedule. Following the second round of reviews, a final version of the interview schedule was confirmed.

The Interview Guiding Questions Schedule had seven sections. The first section elicited demographic data, which was collected mainly from the Expression of Interest form. The introduction section explained the structure of the interview, confirmed expectations of the interview and sought consent. The background section asked the participant about living arrangements, hobbies, friends, occupation, disability and communication methods. This section aimed to allow the interviewer to build rapport with the participants before approaching more sensitive aspects of the interview. The following two sections explored the participant's social life, social relationships and sexualities. In the main part of the interview, which was the sixth section, the guiding questions were based on the components of the ICF model. The questions invited participants to describe several different experiences when they had attempted to develop romantic or sexual relationships. The closing section allowed participants to add further information, which included providing dating recommendations to others with complex communication needs. An outline of the interview guiding questions was sent to participants beforehand to provide them with sufficient time to prepare their responses.

Originally, the intention was to allow up to three hours per interview and for the interview to be conducted over multiple sessions. This was revised so that the interview could take up to two hours, which could be conducted over multiple sessions, with an optional follow up of up to one hour. This strategy was designed to enable any issues arising from the transcript to be clarified and discussed while allowing the participant to contribute any additional information. However, this option was not used because the two hours did not give adequate time to explore the experiences discussed by the participants. Most of the interviews involved a full three hours, and no-one raised any issue requiring a follow-up from reading the transcript.

5.5.2 Interview Process

The researcher negotiated the times and places of the interviews to suit the needs and preferences of participants, the researcher and assistants. It was important that the locations of the interviews were sufficiently quiet for communication and private enough to talk freely. The participants were given the option for the interviews to take place either in person or using an online video-conferencing application, Skype. Interviews with most participants from interstate and overseas occurred using Skype. To maintain the researcher’s privacy, a separate Skype identity was set up. The User Name was Researcher.Sellwood. This ensured that participants could only contact the researcher when appropriate. Most telecommunication interviews were conducted from the home office of the researcher with his academic assistants. However, on one occasion, due to his internet access becoming temporarily unreliable, the researcher had to relocate to an office in his local church where he was assured of privacy. One participant was visiting Adelaide and chose to be interviewed in person, so a room was booked in the university's city campus.

One of the additional considerations, alluded to earlier, was the need to confirm participants' ability to give informed consent (Balandin et al., 2006). This was achieved within the introduction section of each interview using an alternative method involving the following five simple questions adapted from the study of Balandin et al. (2006). These required Yes/No responses testing their knowledge from the Participants' Information Sheet:

- Do you have to participate in the study, "An investigation into the experiences of people with complex communication needs in developing romantic or sexual relationships"?
- Can you say that you want to stop being interviewed at any time without repercussions?
- Could you be interviewed over several sessions?
- Will your name appear in any publication of this research?
- Can anyone else access your answers other than [the researcher], his academic assistant and three supervisors?

Originally, the participants were required to have returned a consent form which had a space for them to sign and a space for them to put their mark if they were unable to sign. A witness, who was not a part of this project, was needed if the participant used a mark. One of the participants raised with the researcher the issue of confidentiality, needing to have a third person to witness their mark. After some research and discussion with the chair of the Ethics Committee, a proposal was submitted and accepted by the Committee to gain consent orally at the start of each session by adding an additional question. The National Statement, Section 2.2.5 (NHMRC, 2007) indicates that signed consent is not required, and can be obtained by other means. In the original interview there was a section seeking to establish that participants could give informed consent by a series of yes/no questions. This was changed by inserting a question, which would be asked in each session, as to whether the participant gave consent to participating in the research.

Another additional methodological consideration was that both the interviewer and interviewees had communication disabilities which added complexity to the interview process. Participants chose the communication modes that they found comfortable. The majority used their own voice and only used their AAC devices to support communication breakdowns. Several used the chat facility of the teleconference software to type most of their responses. More than a third used communication assistants to support communication and elaborate on details at the request of the participant. The interviewer made a conscious effort to listen to participant responses, to ensure that the voice of the participant with complex communication needs was the predominant one. If participants chose to use a communication assistant, they were encouraged to have a competent person who they trusted to support them.

The researcher used an academic assistant provided through Flinders University to support him to conduct the interviews. Initially, it was considered important to use the same academic assistant for all interviews in order to maintain confidentiality and provide consistency. As it became apparent that the primary academic assistant would not always be available, due to interview times being set for the convenience of international participants and because of other unforeseen events, an additional assistant was sourced. They were both issued an Introductory Letter, Information Sheet and Consent Form (see Appendix 23, 24, 25). There was only one interview when the additional assistant was required. Under the researcher's direction the assistants set up audio and video recording equipment and assisted the researcher with communication. The researcher's primary academic assistant assisted him with transcribing all the interviews.

The researcher used a combination of his communication device and his own speech in the interviews. In preparing for the interviews, he pre-programmed his AAC device to have the interview guiding questions, as well as some probing phrases and questions like “Please elaborate.” and “How did it make you feel?” His academic support worker assisted with communication breakdowns, when there were difficulties in understanding him. However, in practice, the AAC device became a liability as it was not reliable. There were times when the AAC would repeat phrases or questions several times, due to dexterity difficulties of the researcher. This was more of a problem when the questions were long, taking up valuable time. Many participants found it difficult to understand the speech of the device and this was made worse when being played through the teleconferencing software. On a particularly warm day, the AAC device overheated and the researcher had to communicate using his own speech. It became apparent that it was more efficient for the researcher to read out the questions and respond to the participants using his own voice and have his academic assistant revoice when necessary. On occasions, the researcher had his academic assistant read particularly long questions.

In preparation for the interview, one of the participants sent the researcher information on four experiences that they wanted to share. Other participants had previously offered to provide copies of presentations that they had developed on topics related to the subject of this research. The researcher had declined these offers because it would have been difficult to ascertain authorship. One of the main purposes of conducting face to face interviews was to be assured that the data was provided by participants and not third parties. There were also questions as to whether it was acceptable to use pre-prepared material within the scope of the project’s methodology. Following discussion with the primary supervisor, it was decided that it was acceptable to use that material. The information from the participant was sent prior to the interview and was a direct response to the interview outline they had received. The interviewer was able to discuss the contents openly as part of the interview to confirm the authorship. To make use of this additional material, the researcher pasted parts of the text into the relevant sections of the interview schedule and discussed it with the participant in the final interview session to ensure rigour.

5.5.3 Interview Transcription

When conducting phenomenological research using interviews with open-ended questions, it is important to record and transcribe the interview accurately. According to Creswell (2012), it requires much consideration and preparation to ensure that all is captured. For this research, it was considered important to use video recording in order to not miss important body language communication (e.g. gestures, smiles etc.), and to assist in transcription. If participants had refused consent for video recording, consent would have been sought for an audio record of the interview instead. All participants gave consent for video recording. A camcorder was used in the face to face interview. Interviews conducted with the teleconferencing software were recorded by using add-on software. When the chat facility of Skype was used, the text messages were inserted into transcripts. Even through the pilot interviews, there were technical issues that put at risk the integrity of the video recording. Therefore, additional strategies were introduced involving a camcorder to record from another screen (the laptop) as well as an audio recording device. The interviews were transcribed by the researcher and his primary academic assistant. Each of the participants was given copies of the transcripts of their interviews and asked to return them with amendments within ten days.

It was critical that the voices of the participants were brought to the forefront, and the use of direct quotes was a key strategy employed to augment their communication. According to Von Tetzchner and Basil (2011), direct quotes of communication from people using AAC were rarely used in papers in the AAC Journal and they recommend further discussion on methods of transcribing such communication. The *AAC Notational Conventions* within the *Manuscript Preparation and Submission: AAC Journal* (ISAAC, 2010) provide style instructions for representing the communication modes used in data collection (see Appendix 26). Many of the participants utilised the chat facility of the teleconferencing software to respond to questions and one, at times, used eye spelling with her communication assistant revoicing their intended message. Neither of these modes was adequately represented in these instructions. Therefore, the researcher decided to create a style in Word to notate direct quotes of these participants.

The first of these, "*Eye-spelling with an assistant relaying the intent*", was notated as italicised with a dashed underline. The convention used for spelling out words was considered inadequate because the participant was communicating large amounts of information. It would have distracted from the meaning the participant was trying to convey, as well as being difficult to read, if transcribed in this way. Furthermore, when the participant converted to using eye-spelling, she would interact with her communication assistant to construct her response before the assistant revoiced it. The communication of the participant could be observed by the researcher, but the spelling was not intelligible as the communication was co-constructed. The second additional style was for "*typed responses using the chat feature of the teleconferencing software*," not using an AAC device, and was notated as italicised with a dotted underline. Many of these typed responses contained an abnormally high number of spelling and grammatical errors, and it would be usual to indicate these by the use of *sic erat scriptum* or [*sic*], yet, doing so could detract from the participants' intended meaning. As it is imperative to capture the totality of the intent in communication (Von Tetzchner & Basil, 2011), typed responses were not edited in any way, to ensure their integrity.

The transcription of the interviews was central to providing a firm foundation for the data analysis, and many steps were taken to ensure its integrity. Interviews were transcribed by the researcher and his primary assistant working together. After each session, the video and audio files were transferred to secure storage. The researcher developed his own transcript template (see Appendix 27), which included the Interview Schedule questions with columns for recording times, speakers, responses and notes. The researcher used the notes column to record significant observations such as body language, gestures, background happenings, communication issues and personal reflections. The recoding times and notes columns were removed from the copy sent to participants for checking. This ensured that the expectations of the participants were clear. The majority returned an email confirming that the transcripts were accurate and that they were agreeable to the transcript content being used. Three returned their transcripts with minor changes that were noted in the master copy.

Another peculiarity of this project was the transcribing of the interviews. Often research projects have interviews transcribed using a standard transcription service. Even though the participants and the researcher used AAC devices, most preferred their own dysarthric speech, which was difficult to understand. The use of a transcription service that was unfamiliar with the speech patterns was not feasible. The option of using the services of a trained speech pathologist was discussed. It was considered that the researcher and his assistant would be more efficient, even though the process was long and tedious, because they were present during the interview and had the contextual information to assist them to understand the speech better. The researcher was present throughout the transcribing of each interview by the primary academic assistant. This enabled him to begin to immerse himself in the data as well as assisting with transcribing parts that were difficult to decipher.

It is usual for interviews of phenomenological research to be transcribed verbatim to ensure their integrity. The first two interviews were transcribed verbatim, with one taking about 30 hours to complete. Most of the time was taken with understanding the speech of the interviewer and the participants and transcribing each utterance including communication breakdowns. A communication breakdown occurs when a communication, typically verbal, is misunderstood. Repairing a communication breakdown means correcting the misunderstanding, which can require multiple attempts from a person with complex communication needs. After transcribing the first two interviews, breakdowns were documented but not transcribed in detail as it was decided that the research was not about communication breakdowns, but about the lived experiences of participants. It was also considered that including every utterance in the transcript would introduce unnecessary and irrelevant data that would serve to distract from the intended meaning and increase the difficult of analysing the phenomenon. Furthermore, participants receiving a copy of their transcript may have interpreted that the research was focusing on their impediment rather than their lived experience, causing some distress.

5.6 Data analysis

Data analysis occurred after the interviews were transcribed and participants had confirmed their accuracy. The data analysis of the interviews utilised the six phases of thematic analysis proposed by Braun and Clarke (2012). These phases are iterative with each phase building on its predecessor. The six phases are: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the Results Chapter.

1. Familiarisation with the data

The researcher spent two weeks reading through each of the transcripts several times; first in the order of the interviews and then in reverse order to enhance his understanding. The transcripts were then imported into NVivo in preparation for coding. As the researcher thought it would be useful to have the individual interview questions coded for ease of analysing each question, the auto-coding feature was used after the transcripts were re-formatted.

Following this an attempt to remove all identifiers of participants was conducted. This included replacing names of places, organisations and brand names of current AAC devices with general terms in square brackets and replacing the name of each participant with a pseudonym. However, reference to the Canon Communicator was left in as the brand is no longer commercially available and it was important to provide context to some shared experiences.

The researcher developed his own Access database to store the participants' information and their status through the project. The data indicated which stage had been completed and was kept separate from the transcripts to maintain confidentiality.

2. Generating initial codes

As it would be useful to have each response coded to the individual participant, communication assistant, academic assistant or research interviewer and to the relevant interview question, the NVivo auto-coding feature was utilised. However, for this to happen, the transcripts had to be reformatted without tables and with the use of styles within Word.

Following the coding of each individual interview question, the step of generating the initial codes began by starting with the open coding and identifying key experiences. These identified experiences were sourced from the interview where participants described attempting to develop romantic or sexual relationships. The experiences were coded individually and placed in a folder called "Experiences" in NVivo. A summary of these experiences was made into a table in Word and used as reference material.

3. Searching for themes

The researcher first read through each of the transcripts, open coding each. In this process he coded every segment that described actions, places, relationships, sentiments, conflicts and other matters of interest. This was the first attempt to find commonalities and, as usual, there was an abundance of codes representing these characteristics. However, the themes generated from the use of the identified codes did not seem to fully reflect the overall sentiment of the interviews. The codes were then analysed using the ICF structure in a separate NVivo folder. This was useful as it identified that many of the barriers and facilitators were attitudinal and this pointed the researcher to consider using the concept of ableism (McRuer, 2006) as a possible lens to create themes. Although this did not produce many new themes, the process of producing notes on each of the identified experiences helped build on the understanding of the data, which informed the formation of the eight initial themes which follow:

1. Self-talk (Am I hot)
2. Let's talk (It's all about communication)
3. Developing Relationships (Finding love)
4. When will I see you (Being together)
5. Pillow talk (This is what we get up to)
6. You cannot do that! (This is what we are up against)
7. Making do
8. Making sense

4. Reviewing themes

In attempting to refine the themes, the researcher decided to take an approach which attempted to reveal the essences of the experiences. He put aside working with the transcripts and, with his existing understanding of the experiences, gained from the analysis at that point, he reviewed them using a table that summarised the experiences. In an additional column, a combination of key words and phrases, five at most, were entered for each experience, to attempt to capture the sentiments and actions observed from the experiences. These included words and phrases such as, longing, responsible partner, rejected, questioning disability and pushing boundaries. From these high-level descriptors, patterns started to emerge which identified the three sub-themes: *Longing for Intimacy; Feeling Accepted but Rejected;* and *Maintaining Autonomy.* These sub-themes assisted in developing the main themes.

5. Defining and naming themes

At this point, the data being analysed was that sourced from the part of the interviews where participants described their experiences in attempting to develop romantic and sexual relationships. It was then realised that it was important to separate the data into themes that would best address the research questions, so the data was divided into two categories. One, in response to the first research question, described the experiences that participants shared. The next, in response to the second research question, described the identified barriers and facilitators. As Braun and Clarke (2012) suggested, the data analysis continued to be an iterative process and the themes in both categories developed and were refined. Initially, the same eight themes appeared in both categories, but it became clear that some differentiation was necessary to address the research questions. The themes had developed as the following:

- Experience Themes
    - Developing Relationships: Going Beyond “Let’s Just Be Friends”
    - Touch Me (Being Intimate and Having Sex)
    - The Power of the Other! (Interference and Assistance/ Hindrance by Others)
- Barriers and Facilitators
    - Personal Attitude and Attributes
    - Interpersonal Participation
    - Intimate Communication
    - The Power of the Other.

On further refining the themes, it was identified that there was a *Power of the Other* theme in both the Experience category and the Barriers and Facilitators category. It became apparent that the contents covered in both themes aligned with the ICF environmental factors, so the *Power of the Other* theme in the Experience category was merged with the one in the

Barriers and Facilitators category. Another Experience theme was created called *Relationships Foundations* which explored foundational reasons motivating participants to pursue romantic and sexual relationships. The theme *Touch me* originally incorporated the participants' experiences of being intimate with their partners. As two strong elements came through, this theme was further divided into two: the first, *Sexual Interaction* relating to physical aspects of intimacy and the second, *Intimate Interaction,* highlighting communication during intimacy. In addition, it was recognized that *Personal Attributes and Attitudes* fall into the Personal factors of the ICF. Personal factors are not categorised and there is some debate as to whether they should be categorised at all (Leonardi et al., 2016). Furthermore, the theme was describing more about the lived experience than the barriers and facilitators, therefore it was moved to become the first Experience theme and parts that were not relevant were moved into more appropriate themes. Finally, each of the eight themes was standardised with informal and formal titles.

The following was the final list of themes:

- Experience Themes
  - Personal attitudes and attributes
  - Relationships Foundations
  - Relationship Development
  - Sexual Intimacy
  - Intimate Interaction
- Barriers and Facilitators
  - Interpersonal Participation
  - Intimate Communication
  - The Power of the Other.

- *Producing the Results Chapter*

In writing up the results, it soon became apparent that despite almost 27 hours of interviews, the participants had discussed only 22 experiences. All participants used AAC, with the majority participating in the interview by using their own dysarthric speech, supported by communication assistants or typing using the chat feature of the teleconferencing software. At times communication was slow and difficult which resulted in minimal data being collected. However, as participants were communicating difficult and complex ideas, and as they are accustomed to communicating as much information as possible using minimum words, the actual data that they did provide was multifaceted. The eight themes emerged from analysis of the data which includes these multifaceted experiences and the conversations about the participants' backgrounds. Some of the participants provided greater amounts of information than others, in particular, one participant, who provided a pre-prepared document outlining her experiences. Because of the small dataset, some of the experiences reported in the results are presented in support of more than one theme.

As previously mentioned, the iterative process of data analysis continued during the writing of the Results Chapter. As these themes were refined, quotes of the participants were used to support their formation.

5.7 Conclusion

This research aimed to investigate lived experiences of adults with complex communication needs in order to gain a deeper understanding and knowledge of their experiences in developing romantic and sexual relationships. It also aimed to identify barriers and facilitators they encounter in their pursuit for intimacy. Employing a critical hermeneutics approach and Feminist Standpoint Theory, the semi-structured interviews were conducted either by teleconference or face to face. There were additional methodological considerations to incorporate in the design of research to those which apply in usual qualitative research, given both the researcher and the cohort had complex communication needs. The processes and issues involved with recruitment, conducting interviews and the data analysis were presented. This research derived perspectives from the voices of those who are rarely heard concerning a very personal and often taboo topic. This was achieved through a set of innovative methodologies and methods, outlined in this chapter, which has resulted in this research making a distinguishing contribution to current research evidence.

6 Results

This research investigated the lived experiences of people with complex communication needs in developing romantic or sexual relationships. Nine adults who had complex communication needs participated in interviews that investigated their lived experiences, including the barriers and facilitators they encountered in developing romantic or sexual relationships. This chapter presents the findings of the interviews conducted. It begins with a description of the participants and is followed by an analysis of the interviews. In response to the first research question, five themes describing the romantic and sexual experiences of the participants are presented. A further three themes identified as relating to the barriers and facilitators encountered in developing relationships are presented in response to the second research question.

6.1 Participants

The recruitment process attracted thirteen expressions of interest through the Participants Information website. The researcher contacted all respondents to ascertain their eligibility. Twelve of the respondents met all criteria. Two of these respondents decided not to participate in the interviews, while another decided to withdraw after the first interview session for personal reasons. Only one respondent did not meet the criteria as they identified as having a visual disability but not a communication disability. Therefore, a total of nine people participated in interviews for the research.

6.1.1 Demographic Analysis

Of the nine participants, six were from Australia and the remaining three were from Canada, the United Kingdom and the United States. The demographic information for these nine participants is presented in Table *6.1*. The gender distribution was three males and six females with an age range from 21 to over 70 years. All had completed at least secondary education and two held university qualifications. Their daily activities included study, employment, day programmes and post-retirement activities. The majority lived independently, by themselves, with paid or volunteer support to assist with their personal care. One participant was still living at home with a parent and sibling and two lived in supported accommodation settings. Four participants were in romantic and/or sexual relationships and the rest seemed not to be in any steady relationships.

As this thesis explored sensitive, personal issues and the AAC field is a closely interconnected international community, its members could be easily identified. Hence, pseudonyms have been used and only general demographic data reported to maintain the confidentiality of the participants.

Table 6.1: Demographic information of participants

Age	**Male**	**Female**	**Education**	
	n	***n***		***n***
21 - 30 years	1	0	High school	3
31 - 40 years	0	5	Diploma (e.g. technical or vocational education or 2-year college)	2
41 - 50 years	1	0	Tertiary degree	2
51 - 60 years	0	1	Post graduate studies (i.e. Masters or PhD)	2
61 - 70 years	0	0		
70 + years	1	0		
Total	3	6		

Country	***n***	**Disability**	***n***
Australia	6	Cerebral Palsy	7
Canada	1	Physical disability from childhood	2
United Kingdom	1		
United States of America	1		

6.1.2 Communication modes

Two thirds of the participants had dysarthric speech and the rest had no speech, yet all reported that they used aided AAC systems. Those with speech generally preferred to use their own voice and used their AAC device to augment their communication. Table *6.2* summarises the aided AAC systems and access methods the respondents indicated that they used. Six participants used dedicated AAC devices, half of them used direct access, using one or more fingers to use their devices, one with eye-gaze control technology, one with a joystick and the last used a head pointer. A third used mainstream devices such as computer tablets, all by direct access and one also used paper and pen. The unaided AAC systems included spelling words using speech, eye-pointing and body gestures. Two reported that they used communication assistants, family members or friends to assist them to communicate when socialising.

All interviews were conducted using teleconferencing software, except for one participant who, while visiting the researcher's residential city, chose to be interviewed in person. In the interviews, the communication mode chosen by most of the participants was their own voice, yet all used AAC strategies to support their communication. Three participants used their own speech predominantly, supported by a communication assistant, using their AAC devices only when they deemed necessary. One used speech and a communication assistant, and another mostly used typed responses in the Chat feature in Skype, from time to time using physical gesturing for quick responses. For the in-person interview, the participant used speech and written notes to manage communication breakdowns. The three remaining participants typed their responses, one using speech as well.

Table 6.2: AAC Devices Used/Access Method of the Participants

	n	**Direct Selection**	**Head pointer**	**Joystick**	**Eye-gaze**
Dedicated-AAC device	6	3	1	1	1
Mainstream (i.e. Mobile phones and tablets)	3	3			

6.1.3 Sexuality and Sexual Orientation

Despite the commonly reported misconception that people with disabilities are asexual, all the participants reported having and enjoying a sex life. Most identified as heterosexual, having relationships with the opposite sex. Two of the males identified as homosexual. Several mentioned that they had experimented with bisexual experiences, mostly in their teen years. When one participant was asked about her sexual preference she said "*I think I am bi. […] Because I have had crushes on people.... Males and females.*" Similarly, another reported that most of her peers at high school, including her, had what she called, "*bi experiences.*" She concluded that she preferred to be with men but said that she was "*a good girl*" who, in her youth, only "*had one or two boyfriends but nothing sexual.*"

There was little discussion of how people formed their sexual identities. A male participant discussed the time in his early 20s when he realised that he was gay. A female participant shared an experience in which she found herself questioning her sexual identity after being confronted with a reflection of her body along with the guy with whom she was interested in furthering her relationship. The following comment was made by another male participant discussing his sexuality:

> *I think about straight men that I know who can't find a woman. And try men. I've tried that and it doesn't work. You have to have a different DNA. [...] I've experienced other men and other men would seek me when they can't find a woman, but that doesn't work because of the DNA.*

Several participants discussed having been sexually active over the course of their lives. For example, one of the older participants discussed still being sexually active in his senior years and reflected on an experience as a ten-year-old boy, walking a girl home and kissing her. Similarly, several of the more physically disabled participants reported having engaged regularly in sexual activities in non-romantic relationships.

6.2 Analysis of interviews

This section presents findings from the thematic analysis of the nine interview transcripts and begins with the first research question. In describing the lived experiences, five themes emerged, namely: *Personal attitudes and attributes* which focuses on characteristics of the participants, *Relationship Foundations* which describes participants' needs for romantic and sexual relationships; *Relationship Development* which concerns the attempts of participants to advance friendships and seek potential partners; *Sexual Intimacy* which raises issues surrounding being intimate and engaging in sexual activity; and *Intimate Interaction* which is concerned with the effect of communication in intimate moments. Finally, the second research question is addressed by exploring the barriers and facilitators identified as impacting on the participants.

As previously mentioned, in the analysis of the nine interview transcripts, twenty-two separate experiences were identified through the open coding process. Most of these experiences were coded from the main part of the interview, where participants were describing times when they had attempted to develop romantic or sexual relationships, but some were sourced from the first part of the interview as they expanded on aspects of their social lives. Experiences that were briefly mentioned and included insufficient detail for analysis were excluded. Table *6.3* presents a summary of those identified as key experiences in the order in which participants were interviewed. To maintain confidentiality, in the table and throughout the thesis, pseudonyms are used, and several of the participants' disabilities have been generalised. When presenting the themes, even pseudonyms have been deliberately omitted in some instances.

Table 6.3: Summary of Identified Experiences

	Experience	Participant	Description of Partner
1	As adults, they were being intimate in bed. He was hesitant to touch her, even though she asked him too.	Amelia	Male with complex communication needs
2	As a teenager, she was in a swimming pool with her boyfriend. He grabbed hold of her and she was uncomfortable with his behaviour in a public place as the situation became intimate.	Amelia	Male with complex communication needs
3	They were in a long-term relationship and could only have physical contact occasionally on weekends where she lived, if support staff placed them on the floor to be together.	Katie	Male with complex communication needs
4	Meeting at a restaurant, they had several dates before becoming "friends with benefits."	Katie	Able bodied male
5	Acting out a fetish, he and a friend, a nudist, would go on the roof of a public building where his friend asked him to undress. They went to bed together.	Samuel	Male with complex communication needs
6	Living on opposite sides of the country, they only saw one another when she was working as his support worker on his business trips. A sexual relationship evolved between them on these trips. Both had marriages which were failing at the time.	Ben	Able-bodied female support worker
7	He regularly used a prostitute over several years. She eventually became one of his support workers. They continued to have regular sex about three times a week.	Ben	Able-bodied female support worker
8	He wondered if there was any connection between having cerebral palsy and having a strong libido, reflecting on partners he had had.	Ben	Multiple female partners over a lifetime
9	They met while playing a sport, she was a teenager and he was 10 years older. He expressed romantic interest in her. They communicated secretly through letters with help from friends.	Jasmine	Male with complex communication needs

	Experience	Participant	Description of Partner
10	An able-bodied male started to dance with her at a concert and they were getting on very well, when other people guided him away from her. She did not see him again.	Jasmine	Able bodied male
11	They connected through a dating website and communicated online before they eventually met.	Jasmine	Able bodied male
12	The first sexual experience with her partner who she met online.	Jasmine	Able bodied male
13	She slept with a male from her group of friends. The other males became overprotective of her, punishing him. She eventually slept with the other males in the group.	Emma	Able bodied male
14	They met at a hotel. At the time, her AAC device was a Canon Communicator that printed on strips of paper. Others collected the printouts, read them and teased her. He ended up living with her for some years.	Emma	Able bodied male
15	They met through a friend and became intimate after a dinner party at her place. He stayed for the weekend. They had a long-distance relationship, however they both saw each other regularly.	Emma	Able bodied male
16	They met at a bar and had three or four sexual encounters.	Oscar	Able bodied male
17	Used LBGTIQ+ dating websites to connect with males for sex and used to enjoy seeing their reaction when they realised he had a disability. Now he is more careful, being upfront about his disability before meeting in person.	Oscar	Able bodied males
18	Met at a sauna he frequented and gave his potential partner his business card. Late one night the partner messaged him. The two of them met over the next few nights.	Oscar	Able bodied male
19	She was active in university politics, and she was keen to progress a relationship with a fellow student, but a reflection of the two in a window dramatically caused her to question her sexual identity.	Sophie	Able bodied male
20	She was teaching her friend sign language and they ended up in bed.	Sophie	Able bodied male

	Experience	Participant	Description of Partner
21	She had a long-time friendship with him, having met through a cousin. Believing that he knew how she felt for him, she hoped the relationship could advance.	Eve	Able-bodied male
22	They had known each other since children and have been dating periodically since being teenagers.	Eve	Male with mild cerebral palsy

The analysis of the experiences revealed nearly half were sexual in nature, ranging from first time experiences, to casual sexual encounters and long-term relationships. Some were relationships which developed from friendship to sexual partnerships, and one was a reflection on a lifetime of sexual activity. Most of these relationships were with able-bodied people.

Twelve experiences seemed to have occurred in the past, such as several during childhood and teen years, or more than a decade ago. Five experiences were identified as occurring within the past ten years, while five were recent at the time of the interviews. Intimate experiences ranged from a friend becoming physical in a pool, to a couple struggling to have time out of their wheelchairs together, to another couple acting out fetishism by getting naked on a roof. Two involved participants meeting potential partners who entered conversation or danced with them. Several experiences involved participants meeting their partners through dating websites. The experiences, together with the information about social interactions and relationships, were thematically analysed to search for commonality and divergence.

In a phenomenological study like this, direct quotes of participants' responses are used to bring to attention the voice of the participants, and to enhance understanding. The *AAC Notational Conventions* of the journal of the *International Society of Augmentative and Alternative Communication* (2010) was used to notate direct quotes of participants (see

Appendix 26). However, the researcher created two additional formatting conventions to accommodate communication modes which were not included in the original notations. "*Eye-spelling with an assistant relaying the intent*", was notated as italicised with a dashed underline. "*Typed responses using the chat feature of Skype*", not using an AAC device, were notated as italicised with a dotted underline. Usually, in direct quotes, spelling and grammatical errors would be indicated using *sic erat scriptum* or [*sic*]. As participants had complex communication needs, many typed responses which contained an abnormally high number of spelling and grammatical errors, and to indicate each of these errors could detract from the participants' intended meaning. Therefore, it was decided not to denote these errors in order to maintain the integrity of responses.

6.3 Experience themes

This section attempts to answer the first research question through further in-depth analysis of the participants' lived experiences. It presents the themes that emerged from analysing the experiences identified in Table *6.3*. These themes are *Personal Attitudes and Attributes, Relationship Foundations*, *Relationship Development, Sexual Intimacy* and *Intimate Interactions*. Section 6.4 will then present factors that have impacted on participants' relationships over time—both barriers and facilitators.

6.3.1 Personal attitudes and attributes

All participants seemed to have high levels of self-confidence and this was reiterated consistently throughout their interviews. They discussed how their romantic and sexual relationships were affected by their personal attitudes and attributes, which included positive self-esteem and determination to maintain autonomy in life.

Participants also demonstrated a strong sense of resilience as they discussed their active social lives and strong self-esteem, yet a lack of self-confidence was also evident at times. Jasmine's experiences at a concert and while playing sport were described by her as both elevating her confidence yet also causing a feeling of inadequacy. She explained how having an able-bodied man show her attention at a concert made her feel sexually desirable, although, she added, "*The whole time I was a bit suspicious of him, thinking I wasn't the real woman he wanted. [...] This made me, in a way, put up a barrier between us [...] until it was too late."* As they were dancing, her friends were concerned for her safety so they had him escorted from the venue. The experience boosted her self-esteem, as she commented, "*He made me believe in myself so I joined an on-line dating site where I met my partner.*" Speaking of another experience where her self-esteem was lifted, Jasmine said she had an admirer who found her attractive while she was playing sport. She recalled, "*He told my mun I was beautiful and asked if he could talk to me.*" Despite this, she lacked the self-confidence to confront her mother over her interference in the relationship, "*I didn't have the ability or will to oppose my mother, who was against me having a relationship with this man."*

Sophie reported having an experience which made her question her identity, in particular, her sexual identity. Having a sense of belonging through university student politics, she felt privileged to be seen with an able-bodied male colleague and she longed for more from the relationship. One day, when they were walking together on campus, she was shocked when she saw a reflection of them in a window and said, *"I saw my body as the world must see me."* Sophie reported that it took her several years to regain her self-esteem from this experience.

Conversely, Samuel and Oscar described how they had the self-confidence to initiate conversations with strangers in social situations. Oscar attributed his outgoing personality to feeling comfortable with starting conversations with others as he states, "*I guess my personality, my AAC, because I will talk to anyone.*" However, Oscar's confidence changed as he aged because of his perception of attitudes towards him. He commented: *"I am a little* *less confident now than I was at 19 because I've seen more, […] Like, I feel like I'm a little bit shy now because I see what people's attitudes are towards me now."*

Emma had: "*always had the attitude I don't care what people think as long as it feels right to me.*" However, she seemed to have lost some confidence in herself, saying, "*if I could have a do over, I wouldn't be as needy for his time.*" Emma pointed out how having low self-esteem could be a barrier to forming relationships, portraying herself as being self-confident yet claiming it was her "*own introversion at times or insecurity would be a barrier*" when meeting new people.

Religious beliefs can influence one's self-esteem and self-confidence and these were discussed as having positive or negative influences in two participants' lives. Eve and Sophie both mentioned that they were involved in faith communities. Eve pointed to her faith as a positive influence in her life by saying, *"First of all, I believe in God. God is a big part in my life. I always say he made me the way I am for a reason and it is my job to figure out what the reason is for."* However, it seemed that Sophie's faith was a barrier, as she said, "*being brought up in church that too did not help.*" She did not elaborate on this but asserted that: "*the next generation after me are much more courageous and willing to break from tradition,*" indicating that she felt restricted regarding her sexuality because of her single status. When asked if she thought it was deemed not normal being out of relationships, she replied by typing: "*when [t]he uniting church did the sexuality report, I thought it was ggreat because it recognised single people.*"

6.3.2 Relationship Foundations

The next theme reflects participants' needs for romantic and sexual relationships, which includes their emotional responses to their experiences. Many encounters suggested a sense of longing for intimacy, the need to be loved and cared for. A pattern also emerged in which participants perceived themselves as being accepted on one hand yet facing rejection on the other. A third aspect of this theme identified that participants needed to discover ways to be empowered despite struggles in their romantic and sexual relationships.

Underlying all the experiences was a longing for intimacy. This included a need for acceptance, love and sexual intimacy. For some participants, it was the need to find a partner while for others, it was the desire to have greater intimacy with a friend or existing partner. For example, Eve talked about how, in her twenties, she wanted to advance a long-time friendship with her best friend's cousin. She explained that they had known each other since childhood and she felt that he saw beyond her disability. Whenever they met they had great discussions and she felt able to confide in him. In Jasmine's case, her yearning for a partner increased after her brief experience at a concert, where a stranger came to dance with her, making her feel desired, only to have it ripped away by others removing him, possibly to protect her. Two other experiences focussed on times when the participant longed to be intimate with another person, but this longing was impacted by external factors. The first of these was Amelia who was in bed with her boyfriend:

> *I was in [bed] with my lover. I asked him if he would touch me. He didn't want to touch me because he was afraid that something might happen. […] He was very afraid because of his parents. That's what I put it down to.*

The second was Katie, who highlighted the importance of the opportunity to have some physical contact with her partner who was also in a wheelchair. Even though they had been together for a decade and were engaged to marry, they were still thwarted. *"We couldn't do much because we were in chairs. […] The staff wouldn't agree to let us spend physical time together outside of the chairs."*

The importance of feeling valued in relationships was shared in many of the interviews, but another aspect of the theme that emerged is the idea of being accepted and then being rejected by others or by the partner. The feeling of being loved, including admired, came through strongly in several of Jasmine's experiences. She expressed her pleasure in the perceived romance of having a fellow sport team member, who also had complex communication needs, romantically pursue her, "*Somehow the situation was more romantic because he had such limited ability and yet he went about pursuing me in the right way,"* before the relationship was curtailed by her mother.

Talking about the incident at the concert mentioned above, she said "*Wow, an able-bodied guy made me feel desirable, sexy, and wanted me physically and emotionally,"* but she perceived that the surrounding people rejected her womanhood by having him removed. On the other hand, Sophie felt accepted by a fellow student for whom she had feelings but, seeing a reflection of her while she was with him, realised he would not see her as a potential partner because of her disability, in this way "rejecting herself". In describing another experience, Sophie outlined how she was seen by a potential partner/friend as someone who was prepared to teach him sign language, but when they ended up in bed together he rejected her as a potential sex partner. In Eve's experience mentioned above, she felt accepted by her long-time friend but was heartbroken when she found that he already had a girlfriend.

Similarly, Emma shared two experiences of feeling accepted by men finding her desirable yet simultaneously feeling rejected because of the attitudes of others surrounding them. In one of these experiences, she was in a relationship with an able-bodied professional, who worked in the Disability field and, even though their relationship existed outside of professional boundaries, his colleagues expressed their disapproval of him dating a woman with a disability.

In the other experience, once again Emma felt accepted yet faced rejection because of interference from others. One evening, at her local hotel, she became acquainted with an able-bodied man. The AAC device she used at the time was a Canon Communicator that printed messages on strips of paper. Although their relationship developed past the friendship level that evening, it was hampered by others thinking that it was fun to disrespectfully read segments of her conversation. Likewise, it was the attitude of others that had an impact on Eve's relationship with her boyfriend, as she said, "*They never ask me but they do go to him and ask him 'Why are you with her?'*" In these incidents, the participants told of feeling loved or being admired by one person, making them feel good about themselves, until they were ultimately rejected by other people. In each case, the rejection could be related to the perceptions of others, seeing the person as operating outside of the accepted social norms.

Another strong aspect of the theme that emerged from many of these experiences was the desire to retain a sense of control. Although participants reported power struggles in their attempt to develop relationships, they nonetheless managed to devise methods to maintain their autonomy. After Jasmine's experience of disempowerment in having a potential partner removed by others, she started using dating websites which allowed her to develop relationships without interference from others. Katie, faced with the restrictive policies of her supported living environment, still pursued several sexual relationships, enlisting the help of a friend to assist her to transfer out of her wheelchair and into bed in one instance. As mentioned in the description of the participants, all seem to be independent minded and strong-willed. In a sense, all of the experiences shared involved a level of empowerment by the participants.

Feeling accepted as a part of her social group, Emma was sufficiently comfortable to initiate sex with one of them, which she perceived as a common practice in the group, yet when other male members found out, she was faced with rejection of her sexuality. "*When i found out i was so mad they couldn't see me as an equal woman to my sisters.*"

6.3.3 Relationship Development

Participants openly discussed their search and pursuit for a lover, including the challenges and opportunities they faced. Some had pursued a romantic relationship with lifetime friends, while many attempted to develop relationships with people they had met, either through mutual friends, at public venues or at work. Dating websites provided another way for participants to find lovers. Though several spoke of friendships in which they were hoping the relationship would advance further, the majority spoke of experiences where relationships passed the friendship stage.

Three participants spoke of experiences with existing friendships which they successfully developed to intimate partnerships, but several failed to flourish into anything more. One such experience in which the relationship did not evolve beyond friendship, despite the hope by the participant that it would, involved Sophie. She described the time when she had been teaching her friend sign language then ended up in bed with him:

> Then he killed me by saying he was not going to make love to me because (I forget reason)... but it was along "lets be goood friends " line........ then at five to 7 next morning he asked me to have sex .... I said I was leaving at 7...... so he missed [h]is chance.

As mentioned previously, most participants described relationships that went beyond friendship and evolved into either romance, sexual relationships or both. Two female participants shared relationships which were continuations of childhood friendships. Both their partners were males with physical disabilities, one having mild cerebral palsy, the other severe cerebral palsy and communication difficulties. Yet, for Eve it was her lifetime friend she was dating at the time of the interview. They were together as a couple on and off over the years and their relationship strengthened through their teens and young adulthood. She said, *“[w]e met at Kindergarten [when we were 3 years of age.]”*. Likewise, Katie spoke of a relationship which began while they were teenagers and her communication assistant explained that her partner was *“the love of her life. […] He died about 11 years ago. And that* *was the significant relationship she had. And they were together for about 10 [years]. He had an accident.”* She later reported that he had in fact died in the accident.

Many participants reported that in developing new relationships, they had had opportunities for meeting potential partners in public venues such as restaurants and hotels, at events, playing sport or through attending university, and these relationships at times evolved to be romantic or sexual. Katie met her sexual partner when she was at a restaurant with friends, some years after the tragic loss of “the love of her life.”

Kate explained, *“[w]hen I first saw him walk through the door of the restaurant then I knew that he was the one for me.*” In the interview she made it very clear that he was a “male friend,” not her boyfriend, so this relationship was not as close as the other one she described, yet the friendship continued with them meeting regularly for sex. Emma also met two of her partners in public venues. The first one,

> *We met at the local pub, i had been going to this pub for years he was new to the area and we ended up hooking up.” In another experience, she described how she met a man at a function and their relationship started some weeks later when she discovered his number which he had secretly programmed into her phone.*

Oscar initiated a relationship by giving a business card to a male who worked at a sauna he often visited, and he described how he met another partner in a bar:

> *So, when I was about 19 I like I remember I was with a couple of friends for my 19th birthday, I met someone at a bar and I said ‘Hello’ to him and I went away with my friends and my friends left me so I went back to the bar and he was waiting for me. But he was very gentle to me… because he was a doctor.*

Jasmine discussed two separate occasions when she met potential partners in public places, both of which have already been mentioned. One was at a regular sports event, while the other was the incident at the concert while she was out dancing with friends. Jasmine explained that she enjoyed the rare occurrence of being pursued and flirted with by a stranger.

> *We danced for ages. He thought I was stunning and wanted to date me. He wanted to know if I found him hot. He was tickling and kissing me, even on the lips. I didn't feel anything when he kissed me but I didn't pull away, either. I was totally engrossed by him. I wasn't able to talk to him and I didn't know how to kiss him back. His touch wasn't perverted, everything he did was about impressing me. He wanted me to hug him and I felt frustrated that I couldn't. He got excited when my friend went away and we were "alone". […] He was such a sweet man and he cared about impressing me and what I thought of him. I ran over his foot and he didn't seem to notice. He tried so hard to dance with me.*

Just when the chance of romance with a potential partner was blooming, as Jasmine hinted in the second quotation above, friends and security staff took it upon themselves to usher him out of the door. Following this night, she tried to re-connect with him but was unable to locate him.

Three participants used online dating sites to connect with potential partners with varying degrees of success. Following the experience of having her relationship thwarted by friends, Jasmine turned to the online environment which allowed her to pursue a romantic relationship without interference from others. She expressed the state of the relationship by saying "*I got to know him without anyone else getting involved. Nobody has managed to take him away from me yet.*" Oscar frequently used LBGTIQ+ dating sites to meet prospective partners, and Emma met a man, through a dating site, who subsequently, fathered her son.

Ben discussed two sexual relationships with professional women. One was with a business trip support worker that developed into a long-term sexual relationship. "*I met a woman I was in contact with about the time my marriage started to fade away and she was in* *a difficult marriage. It was really exciting because we lived across the country but we travelled together."* The other relationship developed with a sex worker and in time she became a support worker:

> *Right now I've had the same prostitute for 12 years. That's probably one of my best relationships. […] This woman is also a [support worker], so I get to see her about 5 hours three times a week. […] We have sex about three times a week. […] She was a sex worker first and after about six years she was here as a [support worker].*

In summary, in relation to developing romantic or sexual relationships that went beyond friendships, it is difficult to quantify the specific number of relationships discussed in the interviews due to the lack of specific information given. In some instances, participants discussed experiences that included an unspecified number of past partners. However, although most had experienced romantic or sexual relationships at some point in time, at the time of the interviews, only two participants were in ongoing relationships.

6.3.4 Sexual Intimacy

All participants spoke of sexual activities and difficulties they faced. The activities ranged from petting in a public swimming pool, physical time together in bed or on the floor, to acting out fetishism in public places. Several participants reported experiencing limitations in these sexual activities due to their disabilities. Participants indicated that they enjoyed having sex yet the opportunities to have it were rare, so, it is possible that many might relate closely to the comment by Eve:

> *Yes, I enjoy sex but it isn't on the forefront of my mind. If it happens I go for days or months and it happens a couple of times a month, I'm OK with that. If it doesn't happen I'm OK with that, too.*

Amelia spoke of an experience when she and her boyfriend, both young adults, were staying in supported accommodation. She explained, after managing to persuade the support staff to put them into bed together, he was reluctant to caress her as she requested. She speculated he was concerned about the possibility of physically hurting her and he was also concerned about how his parents would react. Then Amelia spoke of another experience which was at the other extreme, where she felt she had to stop another boyfriend from fondling her, saying:

> *It was in the pool and he had hold of me and he asked me if it was OK and I said yes. But I could tell that there was something wrong with him but he didn't want to stop so I made the call and it was very hard for me to do this.*

Katie, talking about her relationship with a male friend and her time with him, said:

> *Well, I'm having a relationship with a man and we are having it all and its hard to communicate when we are in bed together when I don't have my communication. [device…] For the first time I slept over I was nervous because I'd never been alone with an able body man before. [After watching a DVD,] I needed to get one of my friends to come to get me into the bed.*

In a previous experience with a male who also used a wheelchair, Katie had also mentioned having to rely on others for the opportunity to have physical intimacy time with her fiancé. At the time she was living in supported accommodation, and although they were engaged to be married, the only time they could be together physically was *"some times on Saturdays*" in the house. Both of Katie's experiences and Amelia's experience in bed, exemplify the lack of spontaneity, due to their disabilities, and the need to make detailed plans well in advance to be able to have physical intimacy with their partners.

Several of the participants were keen to share their theories regarding sexuality and disability. Ben, reflecting on his sex drive, suggested the possibility of a connection between libido and cerebral palsy because both involved the brain, by saying, "*I wonder if something about my CP increased my libido. At the other end of the spectrum, I am surprised I was still* *interested in sex [as many] men my age are no longer interested in sex.*" Ben also theorised that having the extra pressure to succeed including the need to compete with able-bodied people increased his sex drive. Samuel discussed a similar theory concerning the sexuality of people with disabilities, especially cerebral palsy, which he called "*independence fetish theory.*" In his attempt to explain it, he responded with, "*I had to be over-independent to be who I am.*" By this he was suggesting that the additional pressure on him to live independently and be a high achiever led him to act out through fetish behaviour. He then explained one the fetishes he had acted out with a male friend. "*He may be very severely impairment but he likes nudism and once convinced me to undress at the back on a college library. And the roof of the college.*" After typing this response, he put his hand over his face to indicate that he was embarrassed. Samuel discussed a fetish in which he role-played a persona who had a greater disability then he actually had. Although, he did not elaborate on whether the practice was a form of sexual expression, he did indicate that it was a form of escapism. These theories were closely related because they were suggesting that in response to the additional stresses of having to live up to expectations of being disabled, and associated physical limitations, people can turn to sexual activities as a form of escapism.

Three participants specifically discussed specific physical limitations associated with their disabilities which impacted on their experiences of having sex. Talking of his relationship with the support worker, who assist him on business trips, and the impact of a medical procedure on his ability to have sex, Ben reported that the operation changed the dynamic in their love making. He explained, "*I could no longer get on top and I noticed that while sex was just as good for me, for some women don't like to be on top all the time. That kind of surprised me.*" As previously mentioned, Oscar used dating websites to meet new people and, when asked if his encounters with these people always resulted in them having sex with him, his response was:

> *Not always, may be 55% of it is sex but it depends on how my body is going, too. Because if I am really tired, like eh know what I mean [...] Well, it is hard for anyone let alone us if you know what I mean.*

Oscar was referring to the effects of a combination of his cerebral palsy and tiredness which made it difficult for him to move effectively while performing sexual activities. Likewise, although not speaking so much about the effects of tiredness, Jasmine talked in detail of the influence of her cerebral palsy on her during sex:

> *Sex is reasonably painful if you're mid-spasm and your partner wants to enter you, even if he sees that you are wet. You take it for granted that, for you, sex is going to hurt. He knows it, too. Then, you finally stop worrying and start wanting him. [...] But I'm actually scared of condoms because I don't know how much more lubricated I have to be before it doesn't hurt when using a condom. So, getting past that fear barrier of, "Can I come when he comes?" and "How will I cope using a condom if he was actually buffering things for me?" is scary for me. Disability sex education would be nice.*

Jasmine's comment speaks to the impact that physical and communication disability can have on sexual activities but also relates to a lack of sexual knowledge connected with her disability. Despite many speaking of enjoying participating in sexual activities, a few participants suggested that their sexual experience was impacted by the lack, not only of general sexual education, but also of sexual information pertaining to their specific disability. While this lack of knowledge can be seen as a result of environmental factors, the personal knowledge of the participants greatly impacted their experiences. Their experiences often required extensive coordination of their own physical movement and of support provided by others.

6.3.5 Intimate Interaction

Communication during intimate moments, such as in bed where AAC devices were more awkward than normal to use, was a common topic. Although all the participants had devices to assist their communication, many shared that they had trouble with communication in moments of intimacy, one reason being that their AAC devices were not accessible to them and low-tech AAC strategies were able to be employed.

Even Sophie, who could use her AAC device in bed, claimed that text communication is not conducive to intimacy by typing, *"I did not like intimate conversations writte or printed.... sign helps*," in discussing an intimate experience when she was using a Canon Communicator. For Katie, "*[communication] was easy. I had my communication device with me, it was quite easy to communicate except when I was in bed it was quite difficult to communicate."* Jasmine reported it was extremely difficult to communicate with her partner while having sex due to the level of spasms resulting from her cerebral palsy. Consequently, she faced sexual health risks as she was unable to instruct her partner about safe practices. Also, Jasmine added, "*I cannot have any face-to-face conflicts, so I suffer the consequence and humiliation of having unprotected sex.*" Through Katie's and Jasmine's experiences in bed, the additional importance of their partners' roles in maintaining effective communication became clear. Katie relied on her partner to take the lead in the activities and to ensure that mutual communication occurred, while Jasmine provided a greater depth of insight through her emphasises on the vulnerabilities of partners with complex communication needs because of their difficulty in communicating.

On the other hand, Oscar claimed with regard to communication in bed, "*Well, we generally didn't talk about what we wanted to do, we just did it,*" and, discussing another experience, *"it was no problem when we were in bed together."* Ben agreed, stating *"That is not difficult because in bed there is no background noise and my speech is best understood."*

Amelia mentioned that she and her boyfriend in the pool could communicate with each other despite their complex communication needs, and her Communication Assistant suggested that often people with complex communication needs have an ability to communicate among themselves effectively because they know each other well.

To respond to the first research question, this section has explored the lived experiences of the participants in developing relationships. It has described the relationship needs of participants, how relationships formed and, in some instances, they became sexual.

6.4 Barriers and facilitators

This section responds to the second research question by identifying the barriers and facilitators that affected participants in forming intimate relationships. The ICF model informed the analysis of the environmental and personal factors.

The following table (see Table *6.4*) summarises the identified barriers and facilitators which are further explored below in greater detail. Those that were classified as both facilitators and barriers are denoted with an asterisk (*).

Table 6.4: Summary of Barriers and Facilitators

Barriers

- Attitude of others towards disabilities
- Denial of choice
- Dysarthric or no speech
- Excluded from sex education
- Exposed to increased sexual health risks
- Family and friends *
- Functionality of AAC Devices*
- Lack of literacy skills of the partner
- Living distance apart
- Parents' attitudes towards AAC
- People's lack of patience
- Public background noise
- Others being overprotective, interfering and limiting opportunities
- Restrictive policies of support providers
- Supported accommodation staff*
- Support workers*
- Table settings and AAC devices
- Text-based communication
- Wheelchair*

Facilitators

- Communication assistants
- Family and friends *
- Functionality of AAC Devices*
- Having good role models of siblings
- Having someone they knew introduce them
- Long friendships
- Mainstream computer technology
- Meeting new people through mutual acquaintances
- Online dating sites, online environments and telecommunications
- Partners with:
    - effective communication during lovemaking
    - technology knowledge
    - disability, sexual disability, awareness
- Sexual disability knowledge
- Shared experience of having similar disabilities
- Supported accommodation staff*
- Support workers*
- Supportive parents
- The quietness of the bedroom
- Wheelchair*

* denotes that the item was identified as both a barrier and a facilitator.

Three key themes emerged from the data: *Interpersonal Participation, Intimate Communication* and *The Power of the Other*. The *Interpersonal Participation* theme explores the factors that impacted on the activities that participants undertook to meet potential partners and to develop their relationships. The *Intimate Communication* theme refers to the issues faced in communicating intimately. The last theme covers the identified influences of other people that positively or negatively impact on relationships.

6.4.1 Interpersonal Participation

The first theme, *Interpersonal Participation*, explores the barriers and facilitators that participants reported experiencing in their attempts to meet potential partners and develop relationships. In sharing their experiences, over half of the participants directly identified their physical and communication disabilities as having a negative impact on their relationships. Participants generally focused on the practical challenges in their descriptions of sexually intimate experiences, rather than on emotional elements. Despite this, they did not dwell on them while sharing their experiences. Many barriers were concerned with communication when meeting new people. The main facilitators were online dating sites, being introduced by mutual friends and assistive technology, such as, wheelchairs and AAC devices.

Participants believed that a negative perception of their communication disability made meeting new people challenging. They reported that first impressions could be extra difficult with dysarthric or no speech. Amelia, who had dysarthric speech, perceived that people were often frightened of the sound and volume of her speech. Oscar said, "*I enjoy meeting people*," yet he reported that "*people's attitude towards people with disabilities" makes it difficult.* Jasmine echoed this sentiment in her comment concerning meeting new people. "*I always thought I was shy but I went to a conference this year and I realised that I am not shy, it's just so hard to communicate."*

In social settings, having someone they knew introduce them was a facilitator for meeting new people. This might be true for most people, yet four participants made it obvious that what they were saying was more the average introduction of an exchange of names. Jasmine made it very clear that, for her to meet anyone new face to face, *"I have to be introduced,"* giving the perception that she could not approach strangers by herself. While Emma and Eve did not rule out that possibility, they seemed to suggest that it was easier for them to meet through mutual acquaintances. Eve inferred that an introduction from friends was useful, *“I think it’s easier when the boys I know already know them it’s easier to meet new people.”* Emma takes it further, suggesting that: “*when i’m with people who know me and i meet new people its an easier transition to getting to know someone.*” Although Sophie agreed, she was not as specific in needing an introduction, but suggested it was useful to have a sociable acquaintance, saying “*it helps if I know someone that interaction spreads wider.”*

The four participants were suggesting that potential relationships are facilitated by having someone who knows them to introduce them to new people because they can provide more information than merely names. The additional information could include common shared interests and their preferred communication modes. In providing this sort of detail, the new person might gain greater confidence in starting a conversation with a person with complex communication needs.

Compared to the rest of the participants, the two participants who were homosexual seemed to have more self-confidence when approaching new people without needing an introduction. Samuel explained that he often socialised with people and proudly shared his technique of engaging with new people by typing, “*Networking, i know how to balance the questions, i have a little bit of understanding on most subjects [...] Its sandwich, me you me you [...] Not me me me.*“ Similarly, as mentioned earlier Oscar had the confidence to approach strangers *to engage in conversation.*

Other factors that impeded communication in social settings were public background noise and people’s lack of patience. Jasmine, talking about the concert she attended, said, “*The music was too loud for me to say more than yes or no*.” Likewise, Samuel said that it was “*Noise*” that made communicating difficult and “*Thats when the iPad comes out,*” to be used as an AAC device. Ben also reported that background noise impeded his communication as his voice weakened and he discussed one of the novel ways he had coped:

> *As time went on and my voice got quieter, I was less able to communicate in public because of background noise. [...] In fact, I went to my 50th college reunion by Skype and had a much better time than I would have had face to face.*

Sophie mentioned that she had "*difficulty [with] noise*" when communicating with new people in public and stated that communication in a social environment was easier if she was in, "*quiet areas, [within] one on one conversations and communication partner with patience.*"

Referring to people's lack of patience, participants commented that people often did not allow them the time they needed to participate in conversation, or even excluded them, due to their disability. Oscar spoke of, *"People not giving me time to communicate."* In response to the question of what makes meeting new people easier, he said, "*My AAC device, and other people being open to communicating. Because not a lot of people are.*" He indicated his frustration with people he is trying to meet by adding, "*And I'm like 'talk to me!'"* Similarly, Jasmine expressed her desire to participate in networking at a conference "*it's just so hard to communicate. I desperately want to but people have no patience."* Sophie gave the example of when she moved from one church to another when "*getting people to listen and be patient, [.... that] was really hard- it took ages.... but aas I became more involved more people talked to me, its a two way process.*" Ben highlighted the additional consideration needed to ensure that positive characteristics in relationships outweigh the negatives, acknowledging the extra effort required of his partners because of his physical disability. *"The women [...] make a big effort to understand me and that was one of the negative valences, that all my relationships ... that helps me begin to understand that relationships require a balance of valences. Positives and negatives."* Participants seemed to be mindful of the impact that having a disability has on relationship building and of additional factors that need to be considered.

As discussed in the experience themes, several participants turned to the online environment and mobile phone technology to meet potential partners. These technologies, which included short message services (SMS), allowed them to have autonomy over new relationships and control first impressions. Jasmine met her partner through a dating site. She reported that the online environment allowed her to develop the relationship on her own terms. On the first face-to-face date the communication was somewhat difficult. However, on returning home they returned to the online environment and communicated well into the night. Emma typed that "*i met my sons dad on a dating site, we met up for a drink and he was in my bed that night.*" Oscar discussed an experience where he gave a business card to a male worker at a sauna establishment. This enabled the worker to contact him using SMS to arrange a late-night date. He explained his use of several gay apps to meet potential partners. Each of the three participants pointed out the level of autonomy they could maintain through using digital technology to establish new relationships.

The autonomy gained meant the participants could attempt to develop new romantic or sexual relationships while determining the time for disclosing their physical disability. Oscar spoke about his experiences of concealing and disclosing his physical disability when using online LBGTIQ+ dating sites:

> *I would arrive and a man would like open the door, look at me and decide he don't want to be with me. It happened a lot. So now I tell people I have cerebral palsy and I ask him if he knows what it is. I have to tell some people about it but if people don't want to be with me because of my cerebral palsy it's not my problem.*

In response to being asked why he thought people reacted in that fashion, he said:

> *It was a lack of knowledge maybe, a lack of awareness. Like because some people have never met anyone with a disability before, so when I rock up I open the door, it is like people not knowing how to react.*

Oscar was then asked about methods he used to try to make them comfortable about his disability. He described having to constantly provide disability awareness raising to his prospective partners in talking to them, building the relationship and encouraging communication.

Once participants had managed to find a partner through advancing an existing friendship, meeting online or face-to-face, they faced further challenges in maintaining their relationship. The frequency of being together was an important factor in building relationships as Emma highlighted in saying *“we kept seeing each other when ever we could.*” She also suggested that living some distance away from her partner created a barrier to being together, “*if i could drive that would have helped.*” For Ben and the support worker who became his sexual partner, there were long periods between their times together as they lived at opposite sides of the country.

In addition to the challenge of increasing the frequency of being together, it was apparent that extensive planning was often required. As previously identified in one of Katie’s experiences, she needed to plan for someone to provide her personal care and to support her to engage in sexual activities with her male friend. In the second experience, for Katie and her boyfriend to gain physical intimacy they had to be removed from their wheelchairs and be placed on the floor in a private place where they could be physically close together, and she had to arrange for help from willing accommodation support staff. Where Katie identified wheelchairs as barriers to physical intimacy, Jasmine’s account of her interaction while dancing at the concert identified the wheelchair as a facilitator, saying it was:

> *more of a prop than the barrier that I’m used to. There was no awkward moment where it got in the way of how he touched me. I drove over his foot once and once he*

> *accidently leant on the controls of my wheelchair and drove me into some bystanders and we pretty much just continued to dance.*

AAC devices were identified as both barriers and facilitators in social settings. None of the participants spoke of their AAC device as a specific facilitator in their pursuit to forming relationships. The most positive comment was Katie's, talking about the factors which assist in social events, *"The [an AAC device brand name] helps, the AAC helps. The people with [me].*" However, she still included in the comment that the people with her assisted her to communicate. Emma pointed out that communicating with AAC devices, especially while dining in a group, is difficult because "*the conversation moves on so quick.*" Emma also identified table settings as barriers to social interaction saying, "*when dining out configurations of tables means i can't talk to everyone at the table, so i sometimes miss ou on having a a chat with someone seated at the opposite end things like that make it harder.*" This is amplified when in a wheelchair, by not being able to move around easily to socialise within a venue where the seating is closed together. Whereas Sophie, being ambulant, carried her AAC device and reported that "*with communication device its really hard to stand and talk.*" She would often encourage people to sit with her: "*generally I prefer to sit down so others come to me because I know others will tire of standing!*" But Jasmine questioned the actual benefits of having a communication device in a social situation, saying: *"Maybe if I had had my communication device […] but I think it might have been more of a barrier."*

In using a text-based communication device, the lack of literacy skills of the partner can impose additional constraints on the relationship. Emma explained that she had to rely on alternative methods to communicate with one of her partners as he had literacy issues. Occasionally she was not able to respond in a timely manner using her text-based AAC device, creating further communication problems: "*i've always said the body talks when it needs to, […] cos he wasn't very literate either, like he had had a rough life, and lived rough,* *but it was very volatile when i couldn't express quick enough.*" Furthermore, Emma illustrated that the lack of privacy resulting from using text-based devices can also inhibit relationship development. In the case she described, "*i was using a canon communicator though, so our conversations, well my parts were recorded and people used to collect the notes n tease me bout them.*" Her device was old technology where messages were printed, but the issue remains relevant with messages displayed on screens.

All participants found AAC devices, including mainstream technology that they used for communication, had limitations to their usefulness and those who could, tended to use their own dysarthric voices, despite their speech being difficult to understand. Many used friends, support workers and family, who were familiar with their speech, as communication assistants rather than using their AAC device. Eve expressed her preference in her comment, *"I use a voice device but I prefer to use my own voice.*" Ben, who relied on his support workers to assist in communication, stated *"My voice is very quiet so I hire [support workers] with excellent hearing so they can revoice because that's a lot faster than my AAC device.*" Katie also indicated that, while she used her AAC when out socialising, she preferred assistance from others "*If staff is with me that can help or if there is someone I know or a family member that communicates verbally they can sometimes help."*

6.4.2 Intimate Communication

This theme, *Intimate Communication,* focuses on the communication barriers and facilitators surrounding being intimate and engaging in sexual activity. Overall, participants reported that they enjoyed participating in sexual activity. As Ben declared, "*I enjoy [having] regular sex. The rest of my life goes better.*" In most interviews the topic of communication within intimate moments was raised. Participants reported that background noise and the inability of accessing their AAC devices in bed were two main concerns. One suggested he could communicate better in bed than in public as his voice could be heard more easily in the quiet.

Others, who could not use their voices effectively, reported that their communication was drastically impaired as their AAC devices were awkward to use in bed. The participants spoke of their, sometimes creative, alternative methods of communicating such as signing, gestures and responding to closed questions. In a few cases, they relied on the able-bodied partner to maintain communication.

The quietness of the bedroom supported intimate communication for some participants. Ben reported that he had little trouble communicating in bed despite the low volume of his voice as long as there was no background noise. Similarly, Oscar stated, "*So it was a little bit of trouble communicating when we went out all night for tea, but it was no problem when we were in bed together.*" He suggested that in some cases, communication is not required as they just knew what they were doing for each other.

Others reported that effective communication was difficult in bed because of their speech difficulties and their AAC devices being inappropriate or unavailable. Some participants reported that they developed their own AAC strategies that they used in intimate moments. While Sophie argued that text-based communication methods were not suitable for intimate conversations, she found sign language a useful alternative. Katie reported communication in bed with partners was an issue affecting the development of her relationships, reporting that she could use her AAC device when she was out of bed but not in bed. She discussed the methods of communication which she used in bed with her male friend saying, "*We had to use yes or no questions*" and "*Going through the alphabet.*" When she was asked if she used any quick gestures she replied, "*A smile registering good.*"

Two participants discussed the communication methods they used in bed with partners who also had complex communication needs. Samuel described the method he used to communicate with his partner as the following: "*When we slept together when if i was unable to see [his face], i put my finger in his mouth., start with 'before L' and [he] would* *bite/suck me to communicate* [*using the alphabet].”* His partner was able to spell out words he wanted to communicate to Samuel—slow process. Amelia talked about being in bed with her boyfriend and said “*He had some speech that is very hard to understand. [...] He had a letter board,*” which they could not use in bed for communication. However, she reported that they mostly used non-verbal communication which included “*His face, and body language, eye movement, hand movement, head movement*.” With another partner who had complex communication needs, she said, concerning their communication, that “*It was easier [because] he and I knew each other.”* She did not elaborate on the type of communication they used.

Several female participants highlighted their significant reliance on their able-bodied partners during lovemaking because of their own inability to communicate effectively. Jasmine emphasized the importance of having a partner who shows her respect while lovemaking and who is open to learning what suits her:

> It is important to acknowledge that when sex happens for people with CP, your spasm, and you just can’t communicate. [...] In my opinion it takes a very special man to make love to a woman with CP without hurting her [...] It helps if he is really very, very open about sex, as he must rely on both her bodily responses and the feedback she gives afterwards.

Jasmine’s comment suggested that it is vital for partners to provide an opportunity, while having sex and afterwards, for open dialogue. Furthermore, this demonstrates the extraordinary trust that participants must have in their partners.

In terms of intimate communication, most participants discussed sexual experiences and reported using mainly unaided communication strategies, such as body language, gestures, closed questions for yes/no responses, and spelling words, while being intimate. The two main reasons for this were their communication devices were unavailable to them in bed, and the use of text to communicate in intimacy seemed inappropriate.

6.4.3 The Power of the Other

This final theme refers to the influence that other people had as barriers and facilitators to relationships for the participants. These included friends, family members (parents and siblings), support workers, professionals, acquaintances, entertainment venues staff and strangers. Overall, family, friends and support workers were often discussed as mostly positive, open-minded and supportive to participants in their endeavours to develop intimate relationships. While they could be instrumental in the relationships of some participants, at times their support became negative, when they became overprotective, interfering and limiting opportunities for romance. A few participants had to contend with the restrictive policies and conservative attitudes of staff of the supported accommodation where they lived in their attempts to be intimate with their partner.

Some participants expressed gratitude towards their parents for the support they received. Three female participants reported that their supportive parents had a positive influence on their relationships. Eve said, "*I have my mom and have my Dad. He finds a way but they encourage me to be who I am.*" Sophie also said, "*I love my parents and I do not want to hurt them. As long as I am safe, I kow they can die happy- Da died four years ago. I owe mmy parents a lot.*" Sophie further discussed the support she was given by her father when she was asked out on a date. It was before speech generating devices, the Internet and social media were available. She typed "*A guy phoned up to ask me out, in the days before SGDs dad had to relay message.*"

Others reported that parents could hinder relationships. Amelia, referring to the support of parents, suggested that they were "*Helping, but they got in the way. Different values, different beliefs.*" It was further stated that these values and beliefs were related to fears and protection issues. Yet, in another experience, she was in bed with her boyfriend and she believed that he was reluctant to touch her intimately because "*He was very afraid because of his parents. That's what I put it down to. […] Yes. He is very protective of his parents.*" Similarly, Jasmine reported that her mother, using stand-over tactics, actively sabotaged a potential relationship with an admirer:

> *I remember her just standing over him in his manual wheelchair. He just had his head down and he couldn't do anything. She told me I'd find somebody. She wonders why I was and always will be guarded about my relationships.*

Communication between them was made difficult as "*I didn't have a communication device because my dad was convinced I'd stop trying to speak if I had one.*"

Emma valued her siblings, "*i think i have had good role models with two older sisters.*" Yet she found that her family was not always supportive of her relationships. She claimed, talking about one partner, that "*my family loved him, the first one they actually approved on, one sister didnt like him, she said he was a dirty old man, but no one will ever be good enough in her books, but he was much older*"

The support of friends was reported to be almost as important as the support of families. Emma mentioned she appreciated that, "*close friends supported my decisions,*" when she was faced with negativity regarding some of her relationships. Frequently participants met potential partners through socialising with friends. Katie met her male friend through mutual friends while at a restaurant. When the relationship became sexual, it was Katie's friend who provided her personal care, which included "*To help me get out of my chair [...] to get me into the bed.*" It was through a best friend that Eve met a guy who she admired, and with whom she formed a long-term friendship, "*I met her older cousin. [...] I liked him because he was the kind of guy who would look past my disability.*" It was when

Oscar was out with friends celebrating his birthday he met one of his partners, as he explained:

> *I met someone at a bar and I said 'Hello' to him and I went away with my friends and my friends left me so I went back to the bar and he was waiting for me. But he was very gentle to me.*

Participants claimed that their friends would assist them in social situations to communicate with people who were not familiar with their modes of communication. This included acting as communication assistants through revoicing and/or explaining their friend's communication mode, and at times friends were willing to advocate for them. Referring to communication while meeting new people, Eve said "I *think it's easier when the boys I know already know them it's easier to meet new people."* Emma said that, if her friends felt she was being discriminated against, they would promote her, saying, "*she's all there upstairs and downstairs.*"

Unfortunately, there were some experiences shared where friends, thinking they were helping, prevented relationships from developing. Although Emma felt she was a part of the group, when she had sex with one of the boys: "*The other guys were very protective of me, and they had a kangaroo court scenario within their rat pack and he was punished for having sex that i initiated.*" Although she did not use the term *ableism*, straight after describing this experience, she wrote "*notion of pwd not being sexual beings, or being overly sexualised [...] is just another example of oppression,*" suggesting the reaction of the other males could have been related to their perception of her sexuality and disability.

Similarly, Jasmine experienced other people making decisions for her without first consulting her. A male started to dance with her at a concert, then they, "*kinda chased him away and I hadn't been able to give him my name. [...] I felt like I'd done something bad.*" They prevented an opportunity for Jasmine to participate in intimacy with a stranger as many of her age do. She acknowledged that he may not have been a *"perfect guy, but I wish I could have had a bit of fun with him."* In this experience, it was the overprotective behaviour of friends that denied her the opportunity and autonomy to socialise with who she chooses. Jasmine expressed her frustration at constantly having her rights being undermined, even by the people who know her well: *"I just hate my right to choose being taken from me again and again."*

As opposed to their own personal qualities which were previously presented under the *Personal attitudes and attributes* theme, participants also reported some characteristics of the partners that further facilitated intimacy. Long friendships and, for some, shared experience of having similar disabilities had a positive impact on their romances. For some, their shared lived experience of having a disability made an important contribution to the relationship. *"My disability is why we are where we are now. Maybe he just likes me to smile,"* Eve exclaimed about her romantic relationship with her boyfriend at the time of the interview. The relationship grew out of a friendship which started in kindergarten and has been intermittent since. Similarly, in the case of Jasmine's admirer who was a fellow boccia player, they both shared similar life experiences of having a disability and she attributed his ability to make her feel attractive as a positive factor in their relationship.

In relation to her current partner, Jasmine explained that his supportive attitude towards her and his technical knowledge were important in the early stages of their relationship. They met through an online dating site and she maintained, "*He actually supported me through the awkward, getting-to-know-you phase, which helped us both feel comfortable with one another. He is good with technology, so he has gotten so many apps to help me stay in touch with him."*

Another hindrance to the development of sexual relationships that participants reported was that they, as Samuel said, were *"somehow excludes from sex education."* There was a perception by the participants that their schools and teachers did not believe that they needed to be taught sex education. Participants also identified a need for sexual education in relation to their specific disability, and pointed to partners' disability knowledge which impacted on the development of relationships. This knowledge includes having general disability awareness, an understanding of the impact a disability has on the relationship and, in particular, understanding of how it might affect sexual activity.

It is also important for partners to have access to this sort of information. Jasmine referred to it as "*Disability sex education*" and implied that her lovemaking is better if her partners had a certain level of knowledge of her communication and physical disability. Oscar identified that having his partner accept his disability was an important aspect of the relationship, saying, *"My physical disability didn't get in the way, but it was so lovely, he was so open-minded."* Yet, in discussing other experiences of meeting men from dating sites, Oscar expressed he grew tired of needing to provide each new potential partner with disability awareness and information on cerebral palsy. Eve agreed that partners of people with complex communication needs require knowledge of their disability and its impact on lovemaking. Eve's advice to others with complex communication needs was, "*if you decide to be in a sexual relationship with anyone, make sure that that person knows about your disability and is able to accept you for who you are."*

Support workers were discussed as being enablers in some situations and hindrances in others. Some participants would use their support workers to provide support in communication while socialising. Samuel stated that his "*personal assistant primilary,*" made communication easier and Ben said, "*I always take a [support worker] to social events.*" In the case of Jasmine's admirer, it was her admirer's support worker who played an active role in facilitating the couple's private correspondence, by-passing the gatekeeper, her mother. "*The [support worker] was very good at doing what she was told and he'd get exactly what* *he wanted."* Nevertheless, as described earlier, Katie had to rely on support workers to be able to be physically intimate with her partner. She found *"Staff made it difficult because of their attitude and values.*"

One of the female participants asserted that decisions were made concerning her body by medical professionals without meaningful consultation with her. Emma reported "*i fell pregnant and i was informed by doctors i couldn't carry a child, i was forced to terminate, that was one impact of physical disability.*" However, she proved the doctors wrong by becoming pregnant again and having the child.

The attitudes of outsiders and strangers were reported to have made it difficult for participants to form potentially romantic or sexual relationships. Oscar believed that, "*it's sometimes people's attitudes, [and] how much awareness people have.*" Emma agreed, typing "*hindrances were again though outside opinions from strangers, and judgements of wh is he with a cripple [...] barriers were if we went out people assumed i was his client or he was my carer.*" Eve's partner, who had mild cerebral palsy, received pressure from others which Eve thought was "*the only big issue*" in their relationship, saying: "*People can't understand why we are together.*"

Furthermore, as mentioned earlier, Amelia identified as inhibitors the attitudes of people she met for the first time because some seemed reluctant to talk to her. "*Because people often are scared because they think I am yelling, and they can't understand when I am not yelling. I always find things difficult because of the impediment."* Along the same lines, Jasmine pointed to her need to keep her body movements under control: "*I need to be calm because when I am spasming I can't do much at all. Other people make me nervous when they freak out. [...] They think that they can't understand, then they freak out and don't try.*"

Highlighting another attitudinal barrier, which prevented him from entering and socialising in certain nightclubs where he could meet other guys, Oscar wrote "*security thinks*

I'm drunk." He explained "*It is a common issue with people with C. P. who are ambulant get mistaken for being drunk.*" When asked how he would deal with this situation, he responded, "*Well, I tell him that I want to talk to the manager because I'm not drunk. It happens all the time in [a city I often visit], but not so much in [my home city] because everyone knows me.*" Likewise, Jasmine had a similar experience, with security staff at the concert making decisions that impeded the development of a possible romantic or sexual relationship. In all these cases, it was the attitudes of others that acted as barriers to the development of relationships.

Negative attitudes included ableism, and was expressed in the way others, predominantly but not exclusively strangers, perceived their relationships. This took the form of disapproval of the relationship or the assumption that the partner must be a parent or a care provider. In Emma's case, the disapproval came from within the disability sector:

> outsiders - outside my circle - their judgements hindered, like [her partner's] best friend said to him once what are ya doing with a gimp n stuff n he got really confused n hurt, like I've always had the attitude i don't care what people think as long as it feels right to me, but that ended their friendship. [...] we kept seeing each other when ever we could, but the barriers were if we went out people assumed i was his client or he was my carer, and then it was becoming known in the sector and he was getting questioned about integrity n stuff.

Similarly, Eve's boyfriend, who had a mild physical disability that was not obvious, was often subjected to similar criticism. When asked if it hurt her, she responded, *"Yea, but I just ignore them now. When I hear people [talking this way] I just hope that they will mind their own business."*

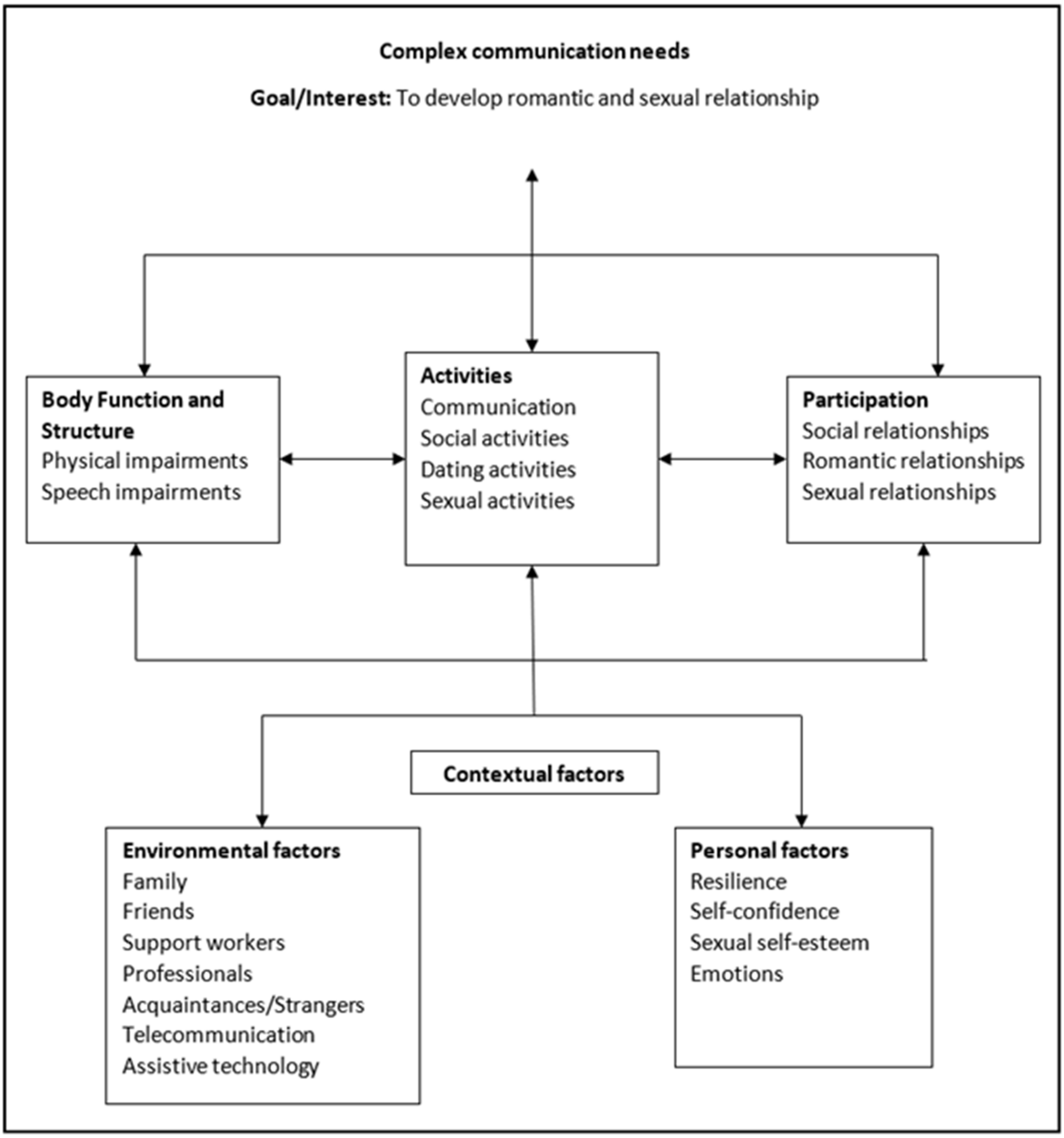
For both Emma and Eve, the attitudes of others acted as significant barriers to their attempts to conform to their social environments. Both were trying to engage in relationships that would otherwise be seen as unremarkable. However, they believed that they were being personally judged as being unable to cope with intimate relationships because of their disability.

6.5 Summary

These results demonstrate that, while the experiences discussed by participants were diverse, they had in common experiences and factors influencing their relationships. Of the nine participants, two thirds were female, most identified as heterosexual, and all were or had been sexually active. At the time of data collection, the majority seemed to be single, but two were in sexual relationships and only two in romantic relationships. While many met partners in places of public entertainment, others met online and some sexual relationships developed from existing friendships and support worker relationships. Their lived experiences in developing romantic and sexual relationships included being physically close, in a public swimming pool, on the floor, in bed or acting out fetishes, such as getting naked on a roof. Five of these experiences were recent at the time of the interviews, five were in the last ten years, and many involved relationships which started during childhood and teen years.

The findings are summarised in the following ICF model (Figure *6.1*). It considers complex communication needs as an impairment and looks at the interplay of factors influencing the achievement of the goal of developing romantic and sexual relationships. The body functions affected were physical and speech impairments. The participants were engaged in social, romantic and sexual relationships that included activities such as communication, socialising, dating and sexual activities. The environmental factors impacting participation were attitudes of family members, friends, and others such as acquaintances and strangers, support workers, as well as telecommunications and AAC systems. The personal attributes with the greatest impact were the participants' resilience, self-confidence and sexual self-esteem.

Figure 6.1: The ICF Model: To develop romantic and sexual relationship



In total, eight themes were identified and presented in this chapter. Five of these themes were responding to the first research question, exploring the lived experiences. These covered personal attributes and attitudes, developing relationships past friendship, meeting new people and becoming intimate. The remaining three themes responded to the second question, identifying the barriers and facilitators affecting the development of romantic and sexual relationships. As discussed, the greatest impacts on participants' relationships were determined to be their own attitudes and those of the people surrounding them. While family members and friends were reported to be generally supportive, acquaintances and strangers often expressed inhibiting ableist attitudes. Facilitators included telecommunication services and dating websites, being introduced to people by mutual friends and having familiar people to assist with communication when meeting new people. Assistive technologies, such as wheelchairs and communication devices, were identified as both facilitators and hindrances in their relationships. It was noted that although participants acknowledged that their disabilities had an impact, they did not see their disabilities as major barriers to developing relationships. All of the participants demonstrated audacity, boldness and courage, persisting in their pursuit of intimate relationships. The next chapter will discuss these findings in light of the existing literature. It will also focus on implications of the findings for practice, and policy and future research.

7 The Discussion

This exploratory research provides an opportunity to hear the voices of nine participants, giving insight into the lived experiences of people with complex communication needs in their endeavours to develop romantic and sexual relationships. It draws on the perspectives of nine adults with complex communication needs and contributes unique knowledge to the AAC field and the broader Disability and Sexuality field. As Shildrick (2009) argues, it is not enough to focus on identifying attitudinal barriers; we need to provide understanding of the causes behind them. Providing this deeper understanding can stimulate conversation and engagement for social change (hooks, 2010).

Following the Standpoint convention, this chapter is written in first person, allowing me to draw on the literature reviews and the research findings as well as my own experiences and knowledge as an 'outsider within' (Collins, 1986). As discussed in the Theoretical Framework chapter, I began with a critical hermeneutics approach as a part of the methodological framework for this project. This approach interrogates power, exclusion and controlling systems at the margins of society through seeking the voices of the marginalised with the objective of achieving social change.

As the project progressed, I realised that Standpoint Theory would enhance the theoretical lens I was using to analyse the data because it also acknowledges the advantage of my status as a researcher who is an 'outsider within' (Collins, 1986). As a researcher who also has complex communication needs I bring my own lived experience to the research. I have also used the concept of ableism, as this consciously interrogates these power systems from a disability perspective. While this is clearly different from traditional methods of research that aim to be objective throughout the process, combining Standpoint Theory and the understanding of ableism enabled me to critically analyse my own experiences and provided me with tools to interpret the experiences of the participants.

The disability and sexuality literature acknowledges that people with disabilities are sexual beings, and that having a physical disability does not necessarily preclude a person from the feelings, desires and needs to be in intimate relationships (East & Orchard, 2013; Hall, 2018). This literature has concentrated predominantly on areas of intellectual and acquired disability (Czapla & Otrębski, 2018; Sellwood et al., 2017; Shikako-Thomas, Bogossian, et al., 2013; Wiegerink, 2010). As the systematic review (see Chapter 2) suggested, the romantic and sexual needs of people with congenital physical and communication disabilities have generally been ignored except in the AAC field which has had an emphasis on protection from abuse rather than on the development of healthy and satisfying intimate relationships.

It has been acknowledged that the majority of research into people with complex communication needs has been in areas relating to clinical practice, education, daily living skills and leisure (Light & McNaughton, 2015). However, as the systematic review and subsequent review of the literature revealed, there has been no significant research within this cohort in relation to adult relationships and sexuality, although there have been recommendations for further research (McNaughton & Light, 2015). The only study that was somewhat similar to this was the doctoral research by Shuttleworth (2000a) which investigated the pursuit of sexual intimacy for men with cerebral palsy.

Early in my PhD candidature, I was a participant in another PhD research project which was also studying the romantic relationships of people who use AAC. They were interviewing participants by email. While this method of interviewing can allow people to respond at their own pace, for participants with complex communication needs it can be quite physically demanding, time consuming and requires a good level of literacy. I withdrew from the project because, after replying to five or six emails and investing over three hours, the structure and time of interview were becoming unclear without an end in sight. In addition to the differing methods employed, by drawing on Standpoint Theory to acknowledge my status as an insider researcher, my research brings a distinctive perspective. Despite the small number of participants in my research, the data collected provides rich insights into the lived experiences of people with complex communication needs in their pursuit of romantic and sexual relationships.

A significant feature of the findings is the degree of ableism the participants faced and, in some cases, internalised, which had direct consequences on their lives. It is common for people with disabilities to have grown up in a social environment where there are negative attitudes towards them, including their ability and sexuality, which they often internalise (Shildrick, 2009). This thesis could have set up an *us and them* dichotomy. However, bell hooks (2010), an American author, feminist, and social activist, warns against setting up dichotomies—us and them, oppressor and oppressed—which are designed to attack the powerful party in each. In her experience of activism, it is more productive to bring about social change by creating understanding and possibilities to form mutual relationships. In this spirit, my thesis aims to provide a deeper understanding of the lives of people with physical and communication disabilities, and through this to stimulate conversation and engagement for social change, acting as a catalyst for future research and future improvements of services.

7.1 The Disability field and the fringes

The purpose of the Disability field is to assist people with disabilities to live satisfying lives and to help them participate in the lives of their communities—but this involves a paradox. There is an apparent assumption that the primary goal is to assimilate people with disabilities into society and enable them to live a life as near to *normal* as possible. The NDIS aims, the Australian government's recent social policy reform, to support people with disabilities to live an ordinary life by offering support deemed to be reasonable and necessary.

However, in analysing the interviews and reading the research literature, it became apparent that the very act of attempting to engage in social relationships requires participants to do things that are not normally required. It could therefore be argued that the attempt to be normal is an abnormal act. The literature suggests that most people with disabilities adapt their sexual activities to their disabilities, thus the act becomes outside the norm (Shildrick, 2009). On reflection, my entire life is outside the norm. Even though I have been raised to try to fit into the wider community, I never really felt that I made it. The very fact that the disability sector attempts to help people with disabilities to fit into society means it operates on the fringes.

Early in the process of analysing the data, it became clear that the barriers and facilitators encountered by these participants in their pursuit of intimacy are intertwined. Many factors identified as facilitators—for example, wheelchairs and AAC devices—were also discussed as hindrances to advancing relationships. In many cases, it is contextual whether a factor is beneficial or an impediment. It is important to acknowledge that people with disabilities always face additional challenges when performing even simple daily tasks. Developing a romantic or sexual relationship can be difficult for anyone, which is why there is a whole industry devoted to meeting potential partners (e.g., online dating services) and maintenance of relationships (e.g., relationships counselling agencies). This is usually tailored for able-bodied persons, to support healthy relationships, but a significant disability can introduce additional issues that need to be managed for a relationship to develop.

Within the Disability Studies field, there are numerous terms used to refer to the cultural systems that are discriminatory against people with disabilities (Bahner, 2018). Although, the term *ableism* was first used within academia in the 1980s, it has only recently been taken up by the broader disability community (Campbell, 2017). At a recent international conference, the father of a man with complex communication needs told me he had never heard the term used. For the first time he had a word that could assist him to name and understand what his son and (although he did not say it), probably he experienced as well. He was relieved to finally be able to name and begin to comprehend this concept. Likewise, many of the participants would have directly experienced ableism in all facets of their lives, yet without having a term by which to conceptualise it, they may not always have understood what was happening and why. Among the participants, only Emma used the term ableism, yet many of the barriers the participants encountered can be attributed to ableist attitudes rather than their disabilities.

7.2 The participants

The nine participants portrayed themselves as strong-willed, resilient, independent thinkers, quite prepared to push boundaries and advocate for others and themselves. This was despite the negative pressure they received from broader society. There was a sense of purpose and a pioneering spirit from each of the participants. They recognised their achievements and difficulties in relationships and wanted to share their experiences for the benefit of others. It appeared that by participating in this research they were not only taking the opportunity to speak about an important part of life but were actually continuing their advocacy work. The participants' active engagement in the interview process and apparent sense of urgency seemed to indicate that the project was perceived as a mechanism to augment their communication on this topic—a topic they believed was important but rarely acknowledged.

The participants openly discussed their search and pursuit of a lover, including the challenges and opportunities they faced, but tended not to focus on their disabilities in doing so. The types of relationships they reported experiencing varied considerably as did the type of sexual expression that they experienced. The main support they received in terms of embarking on romantic and sexual relationships came from friends and family. However, ableist attitudes were the biggest hindrance to developing those relationships. The personal attributes of the participants, such as resilience and determination, appeared to contribute to their drive to be in romantic or sexual relationships and the findings highlighted the additional effort these people put into being able to realise their desire for sexual intimacy.

Participants said little about their emotions when discussing their attempts to develop romantic or sexual relationships. Most of the information given was factual. When feelings were raised, the predominant emotion was frustration. Once again, this could reflect the participants' personality types. Other possible reasons include a desire to contribute as much as possible in the limited time available in the interviews; perhaps the topic invoked deep emotions they did not want exposed; or possibly participants were not comfortable talking with me as a fellow AAC user and researcher. The uniqueness of the power structure might have been too different to what they were used to, and the limited time frame did not allow them time to settle. Despite this, when analysing the interview data, there was a clear pattern of people feeling accepted but being rejected which seemed to indicate that there were deep-seated emotions associated with their experiences.

All participants reported having had sexual experiences and the majority, at the time of the interviews, were sexually active despite the severity of their disabilities. The research also revealed that, as a part of their lived experiences, people with complex communication needs had additional factors to contend with in their attempts to form romantic and sexual relationships. It is noteworthy, that even though the participants were asked about their social lives in the interview, the majority did not talk about any particularly good friends and if they did, the friend was a sexual partner or a potential partner. This may have been because their communication difficulties meant that they attempted to answer the early questions as briefly as possible and not elaborate on them. However, it could also suggest that, although they perceived themselves as well connected, they may have had limited opportunities to form close friendships. While participants often referred to their circle of friends and the social events that they participated in, it is difficult to ascertain the quality and quantity of the opportunities they had to meet new people, an important aspect of meeting potential partners. Exploring the development of friendships could be an area for longitudinal research in the future.

7.3 Developing Romantic and Sexual Relationships

This research confirms that people with variants of types of complex communication needs do participate in romantic and sexual relationships. This section discusses the types of sexualities and relationships of which the nine participants spoke, followed by the five factors that were significant in many of the experiences shared. These factors were classified using the ICF model and identified as Contextual Factors. They include: the attitudes of the participants and of others; the assistance of support workers and the policies they are mandated to work to; the use of AAC strategies and devices in intimate settings; access to sex and disability education; and the resilience and determination of the participants.

Each of these could be considered as facilitators to the development of intimate relationships but, as the results indicate, facilitators identified could also act as barriers. Some of these facilitators also provided significant hindrances to participants' pursuits for intimacy. The predominant barriers experienced by these participants emerged from underpinning ableist attitudes of other people. Exploring these impeding and facilitating factors has yielded a deeper knowledge and understanding of the lived experiences of people with complex communication needs.

7.3.1 Sexualities and need to be in relationships

The sexuality of people with complex communication needs can no longer be ignored. Over the past 40 years of development of the AAC field, the driving force has been to enable people to participate in their communities, with a strong focus on daily living, education and employment but with little mention of sexual participation (McNaughton & Light, 2015).

This research substantiates the fact that people with complex communication needs have the desire and need to express their sexualities, yet acknowledges they encounter significant extra challenges beyond those faced by people without disabilities. The types of sexualities and relationships the participants described reflect shifts in the general population and differ from the "heterosexual, monogamous, full of unconditional love, [able-bodied] and male sexually dominated" (p. 2) types of relationships previously deemed to be the accepted norm (Aumer, 2016). Many relationships were of a romantic nature and were possibly sexual. Their partners were characterised by their diversity; some were able-bodied, some developed from existing friendships or existing work relationships, and numerous relationships began online through dating websites.

Two of the relationships were non-romantic and two participants engaged in homosexual sex, all of which Jonason and Balzarini (2016) refer to as casual sex. Female participants seemed to have more traditional romantic and sexual relationships than males, with two females in current relationships. This reflects to some degree the findings in Retznik et al. (2017), where the females in the cohort had a higher likelihood to be dating. It seems reasonable to a degree that in this current generation, the confidence of females is higher than in previous years and has increased the probability of them being in relationships (Jovanovic & Williams, 2018). Two female participants, Eve and Jasmine, have male partners and presented as having high self-confidence. Samuel and Katie spoke about relationships that were based more on occasional sexual encounters than being in serious long-term relationships. These participants clearly demonstrated that their sexualities are a vital part of their lives, actively seeking and forming intimate relationships with disabled and able-bodied partners.

7.3.1.1 Relationships formed out of friendships

Friendships can change over time, sometimes developing into intimate relationships (Jonason & Balzarini, 2016). For people with complex communication needs who often have limited opportunities to develop broad social networks, existing friends can be potential partners. Several participants discussed friendships which they had hoped would develop past being “just friends” with a few successfully advanced past the friendship stage. Those that did not advance tended to be friendships with able-bodied people whom they met in adulthood. Sophie spoke of two such friendships, one with a university peer and another with a friend she was teaching sign language.

It is difficult to isolate the possible reasons for these relationships not advancing. Perhaps the two did not perceive Sophie as a potential partner, or the friendships lacked the closeness needed to develop into something more. Possibly the friends had ableist attitudes, conscious or unconscious, towards dating someone with a disability. Alternatively, Sophie may have had difficulty communicating her desires safely to the men. She may have lacked the self-confidence, due to her disability, to attempt to advance the relationship (M. McCabe & Taleporos, 2003).

Eve also discussed a friend she had wanted to date but indicated she had not been successful in doing so. In this case, the depth of the relationship seemed to be part of the reason for her attraction. She revealed they had been friends for a long time and she enjoyed the closeness they seemed to have when they were together. Eve reflected on possible reasons he may not have wanted to advance the friendship, suggesting that he could potentially have had concerns about dating someone with a disability. She expected he would have read her signals and understood her desire to advance the relationship. However, she also wondered if she did not communicate to him sufficiently her feelings for him.

I can relate to Eve's difficulties with communicating her desired intentions in wanting to advance a particular friendship. On some occasions when I have attempted to do so, I have tried to communicate my desire to escalate the relationships through holding hands, physical closeness and flirting. Yet, like Eve, I found it difficult to know if the friends understood my intentions. As well as the usual awkwardness in anyone's attempts to develop a friendship into something more, communication and physical disabilities bring additional complexity to the situation. As a person with complex communication needs, it is difficult to know if the other person is simply misreading the signals, resulting in the interaction being misinterpreted as play and not taken seriously. When I told a friend years later I had held strong feelings for her, she was surprised and told me she was unaware of my feelings, although I thought at the time my flirting had been overt. Conversely, there have been times when I have misread the intentions of a helpful, well-meaning friend, believing their feelings for me were deeper than they really were.

The friendships that did evolve into something more tended to be with partners who had been friends since childhood and who also had disabilities. Eve discussed her friendship with her partner at the time of her interview. The two had known each other since pre-school, and he had a minor physical disability. Similarly, Katie's relationship with her fiancé, who has a similar disability to her, began in their childhood. As both couples met at school, there was a sense that these relationships were more stable than most of the others reported.

7.3.1.2 Partners with and without Disabilities

Participants revealed that most of their partners were able-bodied. Although they were disabled themselves, many tended to discriminate based on abilities. Some preferred to have able-bodied partners and others preferred disabled partners. This echoes the findings of Hall (2018), in their analysis of posts on a disability specific online community website by users with disabilities from within threads on *sex* and *sexuality and disability*, where many people indicated they would only have sex with able-bodied partners. Katie, one of my participants, seemed proud that she was able to start a sexual relationship with an able-bodied man and portrayed a sense of achievement in having an able-bodied partner. It seemed that she had crossed a line of some kind and demonstrated that she could be part of the wider community. Hall (2018) proposed that this preference for able-bodied sexual partners could be because the disabled body is not attractive to them. This could be a form of internalised ableism, with people embodying the ableist attitudes that surround them. Another possibility is, living in supported accommodation, most of Katie's social participation was with other disabled people, so breaking through that barrier would be something to celebrate.

Although many discussed relationships with partners who were able-bodied, the relationships where the other partner had a disability seemed to have deeper connection. As reported in *The Power of Other* theme, both Eve and Jasmine expressed that having relationships with men who had disabilities meant that their shared experiences of living with a disability enhanced those relationships. As couples, they could understand each other better and empathize with one another in their disability-related struggles, including encountering ableism. Likewise, as Amelia and Katie discussed their relationships with partners with similar disabilities to them, having this shared lived experience strengthened their relationship. Both women lived in supported accommodation and socialised frequently with others who have similar disabilities, which would increase the probability of them forming intimate relationships with partners with disabilities.

While I have been in relationships with both disabled and able-bodied partners, I grew up with a kind of ableist attitude, in that I mainly wanted to date able-bodied women. I perceived that having an able-bodied partner would somehow make things easier, as she would be able to attend to some of my needs, reducing my reliance on external support staff. However, my experiences with several partners with a disability has changed my attitude.

The first two such relationships began at events where there were many people with disabilities and quickly escalated to romantic relationships. These experiences helped me to realise that it was possible for me to date a woman living with a disability. One developed out of a friendship and, as Eve suggested, the relationship was made stronger by our shared experience of having a similar disability. Yet, as in Eve's experience, my partner faced criticism due to external ableism which, unfortunately, I believe led to the eventual failure of the relationship.

The phenomenon of people's preferences for partners who have a disability, or who do not, goes beyond the scope of this thesis. The findings suggest that most of the participants preferred to have an able-bodied partner in order to benefit from the freedom arising from the assistance that partner could provide. However, a partner with a disability can enable the relationship to be deeper because of the shared experiences of living a disability.

7.3.1.3 "Friends with Benefits"

I was surprised to find that some participants had arrangements, so they could regularly engage in non-romantic sexual relationships with an able-bodied person. These relationships could be referred to as "friends with benefits" (Jonason & Balzarini, 2016). After Katie's previous partner of fifteen years died, she did not seem interested in a romantic relationship but still recognised her own sexual needs, thus her insistence in the interview that her partner at the time was a "male friend", not a boyfriend. Ben reported he had sex several times a week with one of his support workers, a possibility which Shuttleworth (2000a) proposed as a viable opportunity for men with cerebral palsy to pursue intimacy. However, given that these are employer-employee relationships, this practice raises ethical issues which need thoughtful consideration, but are beyond the scope of this thesis.

While these two sexual relationships would once have been considered risky and outside social norms, scholars have noted the social shift in attitudes towards making casual sex acceptable behaviour (Jonason & Balzarini, 2016). However, because both participants were severely physically disabled, this kind of behaviour may still be deemed unacceptable due to the ableist attitudes of others (Shildrick, 2009). As in many of the experiences shared, this showed that participants were prepared to push social boundaries in order to exercise their rights to express their sexuality and to participate in intimate relationships.

7.3.1.4 Diverse Sexualities and Cerebral Palsy

Two of the participants and I have independently observed that there seems to be a higher percentage of people with cerebral palsy with diverse sexualities than in the general population. This is closely related to the topic I had originally intended to research for my PhD, drawing on the Queer Theory I had been introduced to during my Honours degree research—investigating the diverse sexuality in this cohort. As reported under the *Sexual Intimacy* experiential theme in the results, Ben and Samuel were both keen to impart their own theories regarding sexuality and cerebral palsy. Samuel referred to his *Independence Fetish Theory* which suggested that the additional expectations imposed on him to live independently and be a high achiever led him to act out fetish behaviour, which he indicated was both sexual and escapist. These expectations are similar to those Hannam-Swain (2018), a PhD candidate with a disability, discussed in referring to the additional expectations that are imposed on people, despite their disability, to perform to a similar level or better than peers without a disability.

Attempting to cope with these pressures and the associated physical limitations, Ben and Samuel proposed that people turn to sexual activities as a form of escapism—escapism from the additional pressure of needing to coordinate their life to be independent. They observed that their peers had a diverse range of sexualities. However, this sexual diversity may simply be a reflection of the general population, with a percentage engaging in alternative sexual activities/relationships. Regardless, further research is required to understand the additional support needed for people in this cohort, such as additional information on alternative sexuality and support required to enable people to participate in their chosen sexual activities.

Ben and Samuel presented an insight into sexual desire and needs of people with complex communication needs that is rarely found in literature. With the significant barriers to forming intimate relationships which this research has assisted to illuminate, the two have discovered ways to enable themselves to increase their wellbeing through experiencing physical pleasure, relieving stress and improving self-esteem (Gammino et al., 2016). This demonstrates innovative methods the participants have used to be sexually satisfied and therefore to enhance wellbeing. Other alternatives for meeting their sexual needs are to be able to masturbate independently, which, due to some disabilities has its own complexities, or seems to be commonly considered as the only viable option, using the services of a sex worker. The latter strategy also has its complexities, the cost for people with disabilities who are commonly on low incomes, moral issues to be considered and, within some jurisdictions, legal issues (Shildrick, 2009). Although these types of friends with benefits relationships may seem to some to be inappropriate, they can be beneficial to people with complex communication needs. Though controversial, further research should be conducted into the possibility of developing a service which introduced interested parties, one having complex communication needs, with the express aim of developing casual, consensual sexual relationships.

In summary, the findings clearly demonstrate that people with complex communication needs, as with the general population, can desire, seek and participate in romantic relationships and sexual activities. Despite popular belief, people with complex communication needs are sexual and enjoy intimacy. These participants revealed a spectrum of types of sexualities, and were determined to express their sexuality and form relationships.

However, in their pursuit for intimacy the biggest barriers they faced were people's attitudes, mostly ableist attitudes, which hindered or even prevented the development of intimate relationships.

7.3.2 Attitudes and Ableism

A key finding was the prevalence of ableism in the experiences reported and its negative impact on the participants' development of romantic and sexual relationships. These ableist attitudes seriously hindered, and in some cases prevented, the development of relationships. However, before exploring the extent of ableism in many of the experiences, it is important to first explore the attitudes of parents and support workers of people with complex communication needs.

7.3.2.1 Parents and Support Workers

The positive attitudes and support of parents, including support workers, were deemed to be critical facilitators to participants in their attempts to develop relationships. This was evident through many of the interviews. Sophie spoke of the support she received, and the reverence she had for her parents. For example, when she was a young adult and landline telephones were in use, her parents provided communication assistance to enable her to converse by phone with a potential boyfriend. Although, Sophie identified this as assistance, having a third person involved, particularly a parental figure, could also be a barrier for intimacy with her potential boyfriend. Eve also spoke about her supportive parents.

These findings resonate with those of Retznik et al. (2017), whose research with young adults with disabilities regarding their sexuality highlighted the importance of support from an early age from family and school staff in the development of intimate relationships. For parents to provide this sort of support to their child with a disability, expressing positive attitudes towards the child's sexualities and need for intimacy is important. It can be difficult for parents and caregivers to arrive at a point where they perceive their disabled child as a potentially sexual being, or that the child could conceivably be in one, or many, consensual adult relationships over their lifetime.

During the period of conducting and writing up this research, there were two notable incidents which illustrate that parents and caregivers of children with complex communication needs have to make the necessary journey to be supportive for their child to develop intimate relationships. The first involved a woman, a mother of a person with complex communication, who had responded to the recruitment material email for this research, posted on AGOSCI listserv (an email group for sharing information about AAC between professionals, parents, other interested people and people with complex communication needs themselves). The mother expressed her concerns that such a research project was being conducted and suggested it was inappropriate to invite people with complex communication needs to discuss the experiences of intimate relationships. She did not mention her child but from her concerns, perhaps the child was young. It seemed the woman assumed that most people with complex communication needs did not or should not engage in such relationships. Her responses also suggested that the research project was grooming young people who use AAC.

The second incident was communicated anecdotally concerning another mother of a child with complex communication needs on the evening after I presented at the 2018 ISAAC Conference. The mother had attended my conference session. Despite the title of the paper stating that the focus of my session was on the lived experiences of people with complex communication needs developing romantic and sexual relationships, the woman apparently heard only the first few sentences before it suddenly, for the first time, dawned on her that her child was a sexual being. Apparently, she did not hear the rest of my presentation because she was confronted by the reality that someday her child would come to have desires and needs of a sexual nature.

The findings suggest that parents can have attitudes which lead them to be over-protective and prevent their children with disabilities from exploring their sexuality (Shildrick, 2009), hindering them in developing intimate relationships. Jasmine indicated that her mother employed “stand-over tactics” to intimidate her admirer who also had complex communication needs. It is unclear whether her mother’s dominance was intended to protect her from an older man, or if she had ableist attitudes that made it difficult for her to recognise the two as potential lovers. Jasmine felt she could not confront her mother over the incident, in part because of the physical limitations imposed by her complex communication needs—under stress communication becomes even more difficult due to the increase of spasms that occur and this affects her confidence—but partly also because of the power disparity in the relationship. Jasmine relied on her mother as an unpaid care provider and could not afford to jeopardise their relationship.

Each of the parents discussed above seemed to be devoted to their child’s wellbeing and may have discussed with teachers and therapists the needs of their child, such as daily living skills, health care, education and, possibly, employment. It could have been that they were so focused on ensuring these basic needs, they neglected to consider the sexual wellbeing of their teenage or adult children. Alternatively, they may have been aware of their child’s possible sexual needs but consciously avoided confronting them.

Most parents of children without disabilities realise at some point that their child will develop into a sexual being. But for a parent whose child has a disability this could be particularly confronting. Communicating about sex and sexuality with a son or daughter is difficult enough without the added complexities of complex communication needs. It is not as simple as parents having supportive and inclusive attitudes. The child needs to have appropriate AAC solutions in place and to have the learning experiences necessary to be able to have these types of conversations before they need to, including the required vocabulary

(Wickenden, 2011). The attitudes of the participants' mothers clearly had a significant impact on the participants' pursuit for intimacy, both positively and negatively.

7.3.2.2 Ableist Attitudes

When I began this project, I did not anticipate that ableist attitudes would be so prevalent within the experiences of the participants. However, the findings showed that they constituted the major barrier. Ableist attitudes were rife throughout many of the participants' experiences, primarily from others, including strangers, friends and family members. Although all of the participants were involved in advocacy work for others who have complex communication needs, neither they nor I specifically referred to ableism in the interviews. It could be that the participants and I are so used to having to deal with ableism, we rarely think about it in our daily lives. Could it be that we are so immersed in it that we do not recognise it? David Foster Wallace told a story about two young fish:

> There are these two young fish swimming along, and they happen to meet an older fish swimming the other way, who nods at them and says, "Morning, boys, how's the water?" And the two young fish swim on for a bit, and then eventually one of them looks over at the other and goes, "What the hell is water?" *(Wallace, 2008, para. 1)*

Wallace was reflecting on how frequently important realities are not recognised, even though they obviously exist all around us and thus often are not addressed. Perhaps the participants and I could ask, "What the hell is ableism?" With ableism so prevalent within Western culture, and all of us immersed in it, we are often oblivious to it. According to McRuer (2010), if disabled people are constantly immersed in ableism they can internalise the ideology. This can be seen in Jasmine's initial reaction to the able-bodied man who began to dance with her, as she was questioning her womanhood and his motivations. She did not seem to believe that an able-bodied male would perceive her as a potential romantic or sexual partner because of her disability. She doubted herself, believing her disability made her less worthy of the attention she was suddenly receiving and enjoying. When Sophie was walking with her desired partner and saw their reflection in a window, it was likely internalised ableism (Shildrick, 2009) that caused her to doubt her attractiveness to him. The ableist attitudes of others were the largest barriers to participants' attempts to develop romantic or sexual relationships, but the participants themselves created barriers through taking on ableist attitudes.

7.3.2.3 The invisible line

While reviewing the findings, I noticed a phenomenon I call "the invisible line". This occurs when a person with a disability perceivably crosses a line which invokes an extreme and unusually negative response within the group. All of the people involved seem oblivious to the existence of the invisible line until it is crossed and, when that happens, the extreme response is often misunderstood. The invisible line gives insight into the pervasive, yet often subtle, ableism in the lives of people with disabilities, and particularly those with complex communication needs. This phenomenon can be seen in two of the experiences reported and, in each, the responses created barriers to relationship development for the participants involved. The two circumstances were Jasmine flirting with a potential partner at a concert, and Emma initiating sex with an able-bodied member of her group of friends. In both situations, the participants believed they were behaving within the social norms of their groups, until the dynamics changed abruptly, and they experienced sudden disapproval from their friends.

There were three key factors in the invisible line phenomenon. Firstly, the person with the disability identified themselves as an equal member of a group of friends and believed that others in the group shared that perception. Secondly, the person behaved in a manner they considered to be the norm for members of the group and that generally seemed to be accepted. Thirdly, at some point while believing they were acting within acceptable group behavioural norms, the person's actions triggered a sudden and extremely negative response from other group members. This response was not clearly understood by any of the people involved. To the person with a disability, it seemed to imply that a different set of standards was being applied to them.

I have experienced this on several occasions, not with barriers to forming intimate relationships but in losing long-term friendships through unwittingly crossing similar invisible lines. The damage caused by these situations could possibly have been minimised if I had understood the dynamics and had suitable strategies at my disposal, for example, pre-programmed phrases in my AAC designed to de-escalate the conflict or to reassure friends that I was comfortable with the unfolding events. It was my personal experiences that helped me identify this phenomenon as I was thinking critically about the similarities in the two experiences shared by the participants. To explore this phenomenon further, let us consider the possible perspective of each party involved.

The participants, two independently-minded young women, were participating socially within their circle of friends, attempting to act and behave as the other members did. Similar to the gender performativity proposed by Butler (2002), it can be observed that people with disabilities are also performing a role within their social group, attempting to "fit in" with established social norms. In their performativity, they always must be mindful of possible barriers they could encounter, but it is not until they face such barriers that their disability comes to the fore (Paterson & Hughes, 1999). They were doing what they considered as normal and socially acceptable. The two women felt accepted and saw themselves as members of the group, but only became aware of the limited expectations the others had of them when they challenged those expectations. Jasmine felt it was okay to flirt with a stranger on the dance floor. Emma believed it was acceptable to have sex with another member of the group. Jasmine discovered that dancing with a stranger who displayed interest in her was deemed unacceptable. There is no doubt Jasmine tried to interject to tell people she was enjoying the situation, yet she was disempowered by the attitude of her friends and felt her choice was removed. Her friends did not ask whether she wanted him to go, they simply had him escorted him away. Emma felt hurt to learn that while it was okay for other members of the group to have sexual relationships with each other, it was not acceptable for her.

The friends probably felt they were being helpful, but their actions unconsciously demeaned the two women, treating them as if they were incapable of making their own decisions. This could be because the friends respected the person but were concerned about their possible vulnerability. The reaction could be a protective response rather than an intentional devaluing of the person. Despite being accepted as members of their groups, both women were seen as abnormal, so their normal behaviour was also seen as abnormal. One perspective of Jasmine's and Emma's experiences is that although their friends accepted them as part of their group, those friends were influenced by underlying perceptions that made them behave in a protective manner. It is possible that they were experiencing discrimination from their friends and other people who were unthinkingly applying stereotypes, such as, that people with severe disabilities are asexual, do not have the same physiological sexual needs as able-bodies and need to be cared for (Gammino et al., 2016).

The men involved were probably left feeling violated and without any real understanding of what had happened. This was definitely true for Jasmine's dancing partner, and probably less so for Emma's friend with whom she had sex. This type of experience would have been quite new to the two men. They were probably interested in having a good time, but when they noticed the non-verbal communication of the women's friends, did not hesitate to respond to the messages involved. It is likely that they were also oblivious to the invisible line they were about to cross with the two women. The two men may have briefly considered the women’s disabilities and may have thought the experience could turn out to be exciting and unique. From a cynical ableist perspective, the men may have seen the two participants as easier to seduce and less likely or able to object, because of their disabilities.

However, ableism was evident when the couples crossed the invisible line and their behaviour was deemed unacceptable. It is unknown if the two men had any prior experience of people with disabilities—although Emma’s partner had known her before their sexual encounter—so the experience of the hostile reactions of the people surrounding them would probably have been unfamiliar. As Jasmine suggested, when her dance partner was suddenly escorted from the event with little or no explanation, he probably had no understanding about what had happened. It is likely he realised he had been a party to something that was deemed socially unacceptable. In both cases, the men would have experienced the extreme condemnation of others for interacting with a woman with a disability, yet conceivably have had no comprehension of the invisible line they crossed nor the ableist attitudes they evoked.

7.3.2.4 Meeting new people

Ableist attitudes of acquaintances and strangers can create barriers for people with complex communication needs. This was evident when Oscar was denied access to nightclubs by security guards who did not know him, preventing him from participating socially within a setting in which he could have met a possible partner. Jasmine’s admirer did not demonstrate any ableist attitudes, however observers of their interaction did, making uneducated judgements about both parties that prevented the possibility of a relationship developing further.

It has been recognised that people with complex communication needs often have limited social networks and are socially isolated (Ballin & Balandin, 2007; Cooper et al., 2009; Dew et al., 2014; Raghavendra et al., 2012). The participants in this study reported many of the usual barriers and facilitators involved in meeting new people, especially in social settings. These include noisy environments, and impatient communication partners. Some participants thought it was their own fault if they failed to communicate effectively. Jasmine revealed that she used to believe that her shyness prevented her from meeting new people, yet, it was while attending a conference that she realised the real barrier was the attitudes of others. She reported that it was there that she recognised that it was the attitudes of others at the conference which prevented her from being able to communicate effectively, rather than her shyness. Many participants seemed to blame their own inadequacy for their small social networks, yet it could be the ableist attitudes of others preventing them from developing new friendships.

It has been reported that due to their involuntary spasms, the physical appearance and movements of people with cerebral palsy can frighten people from socially interacting with them, thus acting as a barrier to meeting new people and making new friendships (Howland & Rintala, 2001; Shuttleworth, 2000b). The men interviewed by Shuttleworth (2000a) mentioned that they perceived they could not live up to western society’s popular media concept of attractiveness, and this made it difficult to approach people for the first time. One of the men specifically mentioned that his dysarthric speech made it difficult for him to express himself, which supports the findings of this research. Amelia believed that people were frightened by her dysarthric speech and its volume. Sometimes when I am out in public, I am conscious that strangers may misinterpret my involuntary facial movements as indicating a lack of interest in engaging with them. Alternatively, I may have misinterpreted their reaction. Perhaps they simply feel uncomfortable about their ability to interact with me.

There could be two barriers here. The first is the possibly ableist attitudes of strangers who do not even consider a disabled person as a potential partner, even though they may be seen as attractive. People with little or no experience of interacting with a person with complex communication needs can form prejudices against them. Fiske and colleagues suggested that prejudices can be formed based on a combination of two factors, warmth and competence (Fiske, Cuddy, Glick, & Xu, 2002). Applying the theory by Fiske et al. (2002), when strangers meet people with complex communication needs, they assume their competence level is low. Depending on their attitude towards disability, they may have a cold feeling towards them, and therefore show contempt, or have a warm feeling, but feel pity for them. Both options create a communication barrier, preventing friendships being formed.

The second possible barrier relates to self-awareness of the person with complex communication needs who may perceive their body as being less attractive than others, affecting the way they present themselves. Participants suggested the support of friends can help to mitigate these barriers in meeting new people and forming new relationships.

7.3.2.5 Ableist attitudes towards partners

It is not only people with disabilities who are subject to ableist attitudes but also the people associated with them (McRuer, 2006). McRuer (2006) tells of Michael Bérubé, Professor of Literature at Pennsylvania State University, who describes experiences of ableism when speaking of his son, who had Down syndrome. When out with his son, Bérubé frequently would feel obliged to advocate on behalf of his son to be socially included, but ultimately would be confronted with ableist sentiments from acquaintances. Despite acknowledging the son's qualities, their ableist attitudes would come to the fore with the suggestion that he, the father, would prefer to have an able-bodied son. Partners of the nine participants experienced similar ableist attitudes. Eve's boyfriend, whose mild disability was not readily recognisable, was subjected to others constantly questioning why he was dating a woman with such a disability. Even Emma's partner, who was working in the Disability field, was exposed to similar attitudes. In both cases, the partners experienced others suggesting they could do a lot better with a partner who was not disabled.

7.3.2.6 Subverting Ableism

The participants did demonstrate means to combat the pervasiveness of ableism in their pursuit of intimacy. One strategy involved having autonomy and self-advocacy in social interactions (Cooper et al., 2009) achieved by the use of AAC devices and with support from others. The participants did report shortcomings in using AAC devices to socialise, similar to those reported in Ballin and Balandin (2007) and Cooper et al. (2009). Chief among these was the time required to generate responses for participation in conversation. Some participants overcame these limitations by having family, friends and support workers as communication assistants in their social interactions. Despite the seeming paradox of needing support from others in order to maintain one's autonomy and self-advocacy in social interactions, this kind of support can give people confidence and social standing and assist them to participate socially.

Being introduced to new people was identified as a facilitator to assist in mitigating ableism. When Jasmine said that she needed to be introduced to be able to meet new people, I understood what she was saying, and it is quite profound. This may seem obvious, but my standpoint and my own experience of attempting to connect with new people allowed me to understand what she meant. I have found that it is easier to meet new people when I have friends with me who can assist in the early stages of a relationship by providing information about me. These friends do not always have to be able-bodied if communication is not impaired. As in my experience in the bar, described in the prologue, Anton was able to provide information to the women within our initial conversations that assisted them in our interactions. Jasmine was suggesting she also needed more than a basic exchange of names. She needed her friends to take a more deliberate approach to introducing her. With her permission, they could have provided greater detail regarding her modes of communication, and some pertinent information which may have provided additional scaffolding for a friendship to develop. This can help to mitigate potential ableist attitudes, negative attitudes towards people with disabilities. The new acquaintance is more likely to communicate with her by understanding how she communicates. This technique of having friends deliberately introduce people with complex communication needs to acquaintances while providing additional support for conversation can increase opportunities to form friendships. This is a simple but powerful facilitator for people with complex communication needs to expand their social networks and increase the chance of meeting potential partners.

Another method of meeting potential partners, mentioned in the *Relationships Development* theme, was the use of online dating sites which increasingly are being used to connect with others (Aumer, 2016). This reflects the changing nature of dating, which once took a more formal form (Aumer, 2016). This recent cultural change could be making it easier for people with disabilities to date (Bennett, 2017). It is interesting to note that participants talked about how they met their partners, yet there was no mention of dates as such. As people with complex communication needs are also using online environments and telecommunication to participate in society (Sellwood, Wood, & Raghavendra, 2012), many are using social networking sites to develop and maintain relationships (Cooper et al., 2009; Dattilo et al., 2008). Three participants discussed using online dating sites to increase their opportunities to meet potential partners, with the two female participants forming long-term relationships. Jasmine raised an interesting point related to managing the effects of ableism. She said going online was an environment where she could be in control by saying, "*I got to know him without anyone else getting involved. Nobody has managed to take him away from me yet."* This control also included the power to decide when and how to disclose her disability. Unlike face to face interactions, the online environment permits a degree of anonymity. The online environment empowers people to disclose information about their disability when they choose to, as the person whom they are pursuing may not be aware of their disability (Bennett, 2017).

A participant, in the study of T. Shakespeare and Richardson (2018), who was homosexual and had a physical disability reported that he found the acceptance in public gay bars was limited but in the online environment, he was able to participate more easily and could flirt more quickly than in person. Oscar and Jasmine spoke of meeting potential partners through online dating sites. As Jasmine suggested, this gave sufficient time to get to know their potential partners and to build a relationship without the influence of disability-associated issues. Initially Oscar would not disclose his disability until meeting face to face. However, he came to the realisation that it was more helpful to tell potential partners about his disability before meeting them for the first time. Emma disclosed her disability only after becoming better acquainted, using humour to overcome possible negative attitudes. This highlights the extra effort she needed to put into developing relationships because of her disability. Both Jasmine and Emma found it easier to allow a partner to get to know them before having to worry about the additional disability-related factors. It would have been useful to explore further in the interviews the methods people employed to become acquainted with their potential partners and how they decided when to introduce the subject of their disabilities.

Given the success of these participants in connecting with and developing relationships with potential partners through online dating sites, little information was gained about the methods they employed. Although the literature suggests that telecommunications and many online environments can present challenges for people with complex communication needs to access and to participate in efficiently (Cooper et al., 2009; Sellwood et al., 2012), the barriers and facilitators to such technologies were not raised in the interviews. This could be because there was not time to explore these elements. As online dating becomes more common in the wider community, future research could assist other people with complex communication needs to employ this technology successfully.

The findings demonstrate that the attitudes of others had a significant impact on the ability of participants to successfully develop romantic and sexual relationships. Positive supportive attitudes of family, friends and support workers were paramount. However, ableist attitudes were the largest challenges for the participants in their pursuit for intimacy.

The attitudes of others played a major role in the participants' success in developing relationships. On one hand, the people who were close to them, such as family, friends and support workers, had supportive attitudes that acted as facilitators, yet on the other hand, they could be overprotective and held ableist attitudes inhibiting relationship development. Believing that their behaviour was in accordance with the norms of their social group, participants found themselves inadvertently crossing invisible lines causing negative reactions because of a collision between their expectations and those of the group. Participants also discussed difficulties in meeting new people, which are often due to ableist attitudes. Despite encountering these negative attitudes, participants had developed strategies for subverting them, ranging from having friends provide detailed introductions when meeting new people, to using online dating sites. It was also acknowledged that partners of participants had to endure ableist attitudes.

7.3.3 Supporting intimacy in the workplace

Support workers play an important role in the lives of people with complex communication needs, including in developing romantic and sexual relationships. The role of a support worker is usually seen as providing personal care, yet several of the participants mentioned the use of support workers to assist in socialisation. As Shuttleworth (2000a) pointed out, dating is a complex activity, especially for someone who needs additional personal care, such as support with eating and toileting, as well as assistance with communication.

One of Jasmine's admirers, a fellow sport player, used his support worker to communicate so he could flirt with her. This included enabling the couple to communicate secretly to bypass Jasmine's overly protective mother. Ben had his support workers assist with communication while socialising because he found using his AAC device was too slow. Samuel, too, used support workers as communication assistants. Relying on support workers for assistance with social participation can be a double-edged sword because while a third person can assist with communication and personal care for the person with complex communication needs, that third person also changes interaction dynamics and can interfere with the development of the relationship (Dattilo et al., 2008; Shuttleworth, 2000b).

Several participants discussed needing assistance, from support workers, to prepare to have sex, which included assisting them to get out of their wheelchairs and undressing. The workplace policies of service providers can create barriers for clients who receive assistance on dates and with sexual activity (Collier et al., 2006; Shuttleworth, 2000a, 2000b). For people with complex communication needs, private places often become public places as they are workplaces for support workers. As a result, people receiving assistance from support workers, whether in a supported accommodation setting or living independently, must contend with additional challenges when developing relationships and expressing their sexuality. The sexual needs of people with complex communication needs have to coexist with the workplace safety of support workers, and welfare of staff generally takes precedence over the sexual expression of clients (Shildrick, 2009). Many service providers do not have policies surrounding these types of service or they are rarely referred to and this ambiguity can put all parties at risk (Browne & Russell, 2005). Support worker agencies need to investigate ways to ensure their policies and procedures facilitate clients' participation in sexual and intimate activities.

Surveillance and regulation by the State is apparent, as the majority of support worker services are funded by governments, and tension exists when public funds are used to support sexual participation (Shildrick, 2009). It seems paradoxical that public money can be used to support many with complex communication needs in their daily life, education, leisure and employment, yet when it comes to the fundamental human right to maintain one's sexual wellbeing, there is less public support. The support systems established to assist people with disabilities in social participation are often the very systems which create additional barriers (Hannam-Swain, 2018). The type of support the system provides can vary according to the location (Hall, 2018), but hopefully this variation will be reduced in Australia with standardisation brought about by the introduction of the NDIS.

People with disabilities often have to navigate government funding systems and agency policies to express their sexuality. Katie had to negotiate the system to have physical time with her fiancé. Having to negotiate support with paid staff, especially when it may fall outside the policies and practices of agencies, further increases the difficulty for people whose communication is already an issue. Katie indicated she often relied on having support workers whose attitudes and values made them open to assisting in intimate relationship activities. Frequently this involved seeking workers who saw their job as including assistance with sexual activities as a part of supporting wellbeing (Hall, 2018; Shildrick, 2009). Finding support workers who are willing and can be trusted to provide this support can be an ongoing challenge, particularly as there is often a high turnover of staff.

The findings confirm that there are situations where support workers can become romantic or sexual partners of the people they support. Although a controversial facilitator, Shuttleworth (2000a) suggested one's support worker team could be a viable source for romantic or sexual relationships. This was proposed in his doctoral research on men with cerebral palsy and the pursuit of romantic relationships. Ben spoke of two sexual relationships with support workers. The first was with a support worker who travelled with him on business trips. The second was more recent, when a sex worker he had been seeing also became his support worker. This is somewhat different from what Shuttleworth (2000a) suggested, but Ben and his support worker have sex weekly while she is working with him. This has been occurring over several years and provides him with frequent consensual sexual activity, which he reported was important for his health and wellbeing. This practice raises many ethical issues regarding employment and providing care. Although I agree with Shuttleworth (2000a) that support workers could be a good source of friendships that may develop into romantic or sexual relationships, I would strongly advise a self-imposed policy that if such a relationship does develop, the employment should cease, in order to avoid issues of power within the employer-employee relationship.

7.3.4 Communication in intimate moments

Not surprisingly, because all nine participants had complex communication needs, communication within intimacy was discussed in all of the interviews and formed a major theme within the barriers and facilitators component. The experience theme *Intimate Communication* highlighted significant barriers to communicating within intimate moments, which includes having sex. Most of the AAC strategies participants used, aided and unaided, had their shortcomings, thus not adequately supporting them in their social communication. This substantiates previous findings in the literature regarding the shortcomings of AAC devices within social settings (Ballin & Balandin, 2007; Beukelman & Mirenda, 2013). However, these findings highlight the issues of communicating in intimate moments, especially when in bed with their partners.

Communication is a human right according to Article 19 of the Universal Declaration on Human Rights (United Nations, 1948). Mulcair et al. (2018) stated, “Not only is communication a human right, it is the essence of what makes us human” (p. 38). They also suggested communication skills play an important role in successful participation in modern society, which includes having positive social relationships. In intimacy, one of the necessary communication skills is the ability to choose the communication mode that enhances the relationship.

7.3.4.1 Choosing the effective mode of communication

Bourdieu (1986) argued that people tend to choose the most appropriate and effective mode of communication to achieve their desired outcomes. The participants showed resourcefulness in knowing which communication mode to use depending on the setting. Many purposefully chose to use their own dysarthric speech to maximise their input into this project. The additional physical and cognitive effort required for people with complex communication needs to communicate so they can effectively socialise and develop relationships should not be under-estimated. From personal experience, at times it can be easy to communicate, particularly when in the company of familiar like-minded people, but at other times it can be quite complex and tiring. It can be especially demanding in a social setting where communication is quick, and others are also vying for their chance to participate in the conversation. Although the participants were not in that kind of competitive environment during the interviews, their determination to be heard was observed in the extra physical effort they put into communicating their responses.

As previously mentioned, the autonomy of the participants was highlighted as essential to enabling their participation within social relationships. This is not only the ability to communicate but also the ability to insist they be listened to, as “Language is not only an instrument of communication or even of knowledge, but also an instrument of power”

(Bourdieu, 1977, p. 648). All participants referred to having a certain level of autonomy within their relationships. However, this was often jeopardised in intimate moments due to poor access to AAC solutions. Although most participants described unaided AAC solutions that they had developed or adopted to communicate with their partners in bed, maintaining effective communication throughout intimacy was difficult.

AAC devices have been found to be effective in enabling people to achieve communication in social settings (Balandin, 2011), but the participants in this research found them to be inadequate in maintaining two-way communication during intimacy. While Samuel discussed the usefulness of AAC software on a tablet while socialising at events, and Katie suggested that her dedicated AAC device was useful in social settings, no participants reported being totally satisfied with their AAC devices. The AAC field has made advances in providing AAC strategies and devices to enhance people's social participation, yet statements by Jasmine regarding her inability to communicate during sex and needing to trust her partner, bring sharply into focus their shortcomings in intimate situations. This could be a reflection on how AAC practitioners, suppliers and developers prioritise their focus or their insufficient awareness of the lived experience of people with complex communication needs.

7.3.4.2 Intimate communication in public places

Restaurants are popular places for people to develop social and intimate relationships, and these are often inaccessible to people with complex communication needs as they are designed without AAC or wheelchairs in mind (Ballin & Balandin, 2007). Emma mentioned that table settings had insufficient room for her to use her AAC device, making it difficult to communicate. She also found it difficult to move around to talk to others around the table, as one would do if they are difficulties with being heard, but movement is restricted by her wheelchair. This is an obvious social participation barrier which makes it difficult to meet new people and develop relationships. Although she was referring to dinner parties, even in a more intimate dinner for two, which is common for couples in the early stages of a relationship, most restaurant table settings do not cater for the use of AAC devices. Restaurants generally set the table for two, so the couple are facing each other. This poses an issue for many AAC users because restaurants are often noisy and having the partner on the other side of the table can mean they are unable to hear or understand the voice of the AAC device. There is also the issue of others over-hearing everything that is said. A potential solution could be to have AAC with dual screens such as a Lightwriter which allows the person in front to read the message being generated. However, these devices are not suitable for everyone, so another solution is for the table setting to be changed so the partner is seated in a position where they can read the screen.

Another issue with text-based AAC devices that is not commonly reported, arises when a partner has poor literacy skills. This increases the difficulty of developing the relationship (Cooper et al., 2009). This was illustrated in one of Emma's experiences when her partner's poor literacy made effective communication with him challenging for her in times of intimacy. During difficult times when tempers rose, she had to manage the relationship by using gestures and body language, which was often not sufficiently timely. Her text-based AAC device did not adequately support her attempts to maintain their relationship.

7.3.4.3 Ability to flirt

The ability to flirt is an important factor in developing sexual and romantic relationships and is often learned during teenage years through interaction with peers (Shuttleworth, 2000a; Wiegerink et al., 2012). People with complex communication needs have limited opportunities to socialise (Balandin, 2011; Dattilo et al., 2008; Raghavendra et al., 2012; Shuttleworth, 2000a; Teachman, 2016), which includes limited opportunities to engage in flirting behaviour, so they often miss out on learning the etiquette of socialising and flirting. The topic of flirting was not raised in many of the experiences shared, however the participants who did discuss it indicated that they had sufficiently high self-esteem and sexual-esteem which Wiegerink et al. (2012) deemed necessary for successful flirting.

Jasmine reported flirting with a stranger she met while dancing. Dancing is a form of augmentative and alternative communication that can be a facilitator for people with complex communication needs to form new relationships with potential partners, because it encourages intimate communication between people that is non-aided and non-verbal. As with my experience in San Francisco which I described in the Prologue, dancing enabled Jasmine and I to flirt with our respective dancing partners by using gestures and body language, without needing to communicate verbally. In Jasmine's experience, she became involved in a relationship that advanced very quickly beyond friendship. It is unknown if she had an AAC device with her, but it is unlikely she would have been able to use one effectively in that environment. However, they were interacting well as they danced and enjoying each other's company.

Jasmine's experience provides insights into the importance of maintaining autonomy in relationships. Her high level of autonomy was evident in their interaction as they danced. They used gestures to communicate as they were dancing and, in this, they would have worked out the beginnings of the power structure of their relationship. We do not know very much about their interactions except that they became close enough for him to start to engage with her by incorporating Jasmine's wheelchair into the dancing. The significance of this may not be readily apparent. For many people with a disability, our wheelchairs are part of us and our identity. For the man to interact with Jasmine as she described, it is unlikely he would have forced himself on her and pulled her around the dance area without some form of consent from her. It is more likely she indicated with facial gestures her acceptances of his actions. It is evident that she had managed to build a relationship with this man.

7.3.4.4 Communication in bed

Communication in bed with a partner was a significant issue as most of the participants were not able to communicate as efficiently as they could out of bed and this raises issues associated with maintaining consent throughout sexual activities. With the right to participate in sexual activities, there is also the right to decline to participate at any time. It is a requirement in some countries, such as Canada, to be able to give verbal consent throughout any sexual acts (Goldberg, 2018).

Accessibility of AAC devices when in bed was a major issue for many participants, so to compensate for this lack of accessibility, the participants were innovative in their communication strategies to facilitate their romantic and sexual relationships. They had devices that were personalised to suit their own abilities and to support their communication needs within their daily activities, for directing their personal care, for undertaking tasks at education or work settings, and for socialising. However, in bed, their devices were either physically impossible to access or awkward to use.

Many of the issues with AAC devices that were identified as impacting on the ability of the participants to socialise, such as speed, positioning and physical separation between communication partners, impacted even more in intimate situations. The device that Sophie used was designed to be used in a range of environments, including in bed. She could physically access her device well in bed, but she suggested that text-based AAC devices are not conducive to intimacy. They could shift the focus away from being corporeal, with less eye contact and less sensuality. She preferred to use sign language which can lend itself to be more sensual, more intimate, as the focus tends to be on partner's arms, eyes and body. Yet, this could mean that any future sexual partners might need to know sign language too, further limiting the number of potential relationships. It would also require the partners to see each other's hands for a lot of the time.

For participants with less hand dexterity than Sophie, communication with their sexual partners in bed was more difficult and complex. Samuel and his partner both had complex communication needs and Samuel needed to see his partner's facial expressions. Communication became a problem when Samuel was behind his partner in bed, so they devised an AAC strategy using the alphabet and his partner biting or sucking his finger to indicate letters. Amelia and her sexual partner, both with complex communication needs, devised a communication strategy that was less sophisticated, predominantly using facial gestures along with body language. It is unknown whether the participants discussed their communication needs before going into bed together, or if they just went ahead and developed their own modes of communication in the moment. However, it does highlight once again that it was important for them to devise an effective method of communicating throughout the engagement as AAC devices are not suitable for intimate communication. It also demonstrated the need for AAC designers and manufacturers to expand the focus of these social participation tools with a greater emphasis on enabling other kinds of intimate communication. More research is needed into innovative ways of improving the design of the human interfaces of AAC devices to enhance intimate communication.

One of the alarming findings about the lack of AAC devices being accessible in bed was the risks that the participants took to engage sexually with their partners. Jasmine was quite explicit in sharing her sexual experiences, emphasising the risks of not being able to communicate adequately while having sex. She explained that having severe cerebral palsy and dysarthric speech, being sexually aroused can increase her spasticity, causing her body to spasm and making it extremely difficult to communicate. When prompted, Katie briefly mentioned that her partner used closed questions that she would respond to, giving a smile for positive feedback. While Oscar and Ben reported having no significant communication problems when having sex, it is feasible that others had communication issues similar to those of Jasmine but did not raise them in the interviews. Jasmine was the only participant who provided prepared text for her interview. This gave her the opportunity to delve into her experiences in greater detail. However, I only realised the significance of the issue that Jasmine raised while transcribing her interview: without an efficient means to communicate during sex, she puts an enormous additional amount of trust in her partner, who is also taking enormous risks.

Activist, educator, and cultural worker Finger (1992) argues that the constant emphasis on preventing sexual assault and abuse of people with disabilities tends to overshadow the need for supporting them to express their sexuality. One of the foundational principles of this research was to focus on the latter, with emphasis on developing romantic and sexual relationships. However, it must be acknowledged that the risk of sexual assault could be a barrier to developing these relationships. Harris (2018) asserts that the latest media focus on sexual assault and sexual consent has been about able-bodied people predominantly and the issues of people with disabilities have been overlooked.

The Stubblefield court case in New Jersey, USA, helped to shine a spotlight onto the sexual abuse issues faced by people with disabilities. The case involved the apparent sexual relationship between a man with complex communication needs and a university professor. The family of the man with complex communication needs, who believed that he was incapable of giving consent, accused her of having non-consensual sex with him. He used the controversial strategy of facilitated communication, which further complicated the proceedings. The case emphasised the seriousness of the risks to the two involved. In some jurisdictions, internationally, there is a legal requirement for the ability to give verbal consent throughout sexual activities (Goldberg, 2018). If the jury failed to acknowledge his ability to give sexual consent, then the professor could face sexual assault charges, regardless of whether their sexual activities were consensual (Harris, 2018). The real injustice would be if he could and did give consent, but the jury did not accept this, and this points to the importance of people with complex communication needs having a means of independently giving or denying ongoing consent. Conversely, a potential sexual partner could possibly decline to enter a sexual relationship with a person with complex communication needs, for fear of being seen as a rapist or being accused by their partner of sexual assault.

Jasmine made clear the power of the partner and highlighted the importance of trust between them. Being able to communicate effectively while having sex is vital for safety, physically and legally, for both partners. For physical wellbeing, all parties involved must be able to communicate their requests to stop at any time. When one partner's communication is severely diminished, the other has increased power and responsibility and needs to be proactive in maintaining communication by being attentive to gestures during sex. Jasmine gave the impression that she enjoyed having sex and indicated that the sex was consensual, but some may question her ability to effectively communicate ongoing consent in intimate moments.

Goldberg (2018) suggested the disability sector could benefit by learning from the BDSM community as they have to deal with many of the same issues of trust and maintaining communication, including on-going consent. BDSM refers to bondage, discipline, dominance, submission, and sadomasochism practices. In the attempt to increase the safety of couples, in particular the need to maintain active consent, future research could investigate whether the communication strategies used in BDSM activities, where one of the partners is restrained and unable to communicate verbally, could be adapted for partners with complex communication needs.

7.3.5 Disability Sex Education would be nice!

Jasmine summarised another important factor that had an impact on people with complex communication needs in developing romantic and sexual relationships with her thought-provoking statement: “disability sex education would be nice.” In her lived sexual experience, her disability had a direct impact on her sexual participation and she perceived that she lacked appropriate information relating to her disability that could have improved her sexual well-being and activity. Samuel asserted that he lacked access to sex education at an all-male mainstream high school. These echo the participants in Collier et al. (2006) who also had complex communication needs and were frustrated at the lack of relationship and sexual education they received as adolescents. Although adolescents with disabilities should receive sex education in their high school curriculum, this research highlights the need for additional sex education which specifically addresses the impact of their own disability on their potential future romantic and sexual relationships.

Samuel spoke of being excluded from sex education which was a part of the physical education classes. As he did not attend these classes, he did not participate in the classes on sex education. This exclusion could have been an oversight by the school’s management, not recognising that he was missing out on an important part of the curriculum. However, he was quite clear that he believed his exclusion was more than an oversight, suggesting that his teachers did not believe they should have to teach him about sex. Hall (2018) might argue that this stems from ableism among the teaching staff who held the assumption that people with disabilities are either non-sexual or unlikely to be in a serious relationship, and therefore do not need such knowledge. Alternatively, East and Orchard (2013) suggest that the teaching staff were uncomfortable in addressing these issues with their students with disability. Another possible reason could be that as it was approximately twenty to thirty years since he was at school and he was the only student with a disability, the staff lacked the appropriate training to make the necessary environment and curriculum modifications for him to participate in the class.

Able-bodied young people gain much of their sexuality knowledge and social skills through talking with peers, but those with complex communication needs have limited opportunities to talk with their peers to explore these topics (K. Anderson et al., 2011; Collier et al., 2006). Participants in East and Orchard (2013) suggested that even among their peers who also had disabilities, young people did not talk significantly about sex in relation to their disabilities. One suggested that the topic was generally an “elephant in the room.” This could be because, for many people with a disability, sexuality is accompanied by strong feelings of rejection and oppression (Finger, 1992). In my youth, there was often talk among my peers with disabilities concerning “who was with whom,” and reference to sexual activities, but it was rarely about coping physically or emotionally, due to our disability. I have had conversations with close friends who have a similar disability to mine regarding the effects of our disabilities on our bodies and our daily lives but rarely on sexual wellbeing. I was fortunate to attend a local high school with an integration program that provided sex education to students with disabilities in addition to the little they received in their regular classes. Our teacher recognised the need for us to have the opportunity to talk openly regarding sexual issues.

The participants in my research suggested that they required disability-specific sex education, in addition to general mainstream sex education. Similarly, when developing romantic and sexual relationships, I found myself in need of sexual information specific to my disability. The next logical question would be how people with complex communication needs gain their sexual knowledge and social skills. Some might confide in support workers whom they trust in order to explore matters of sexuality (Collier et al., 2006), but this is likely to be beyond the support worker’s role and skill set. The young people in East and Orchard (2013) searched online to obtain anonymously the sexual information they needed, but this requires independent and private internet access which is unavailable to many with complex communication needs.

Retznik et al. (2017) claimed that there was a correlation between success in romance and sexuality for students with physical disability, attending a mainstream school with appropriate additional support staff, and having supportive teachers and parents. The participants in my research talked little about their schooling, but when they did, it was apparent that they did not receive this type of support. Bahner (2018) suggested that, in addition to current sex education, all students could benefit from access to extra curriculum pertaining to disabilities and sex. It should be noted that people with the same disability can experience their disability in different ways, and their individual environmental factors can also change how their disability impacts on experiences. However, there are some experiences shared by people with the same disability. One example is that people with athetoid spastic cerebral palsy lose the ability to effectively manage their saliva when excited. When I learned this recently, my thoughts went to an awkward moment I had with a sexual partner who was uncomfortable with the amount of saliva I was producing. This sort of vital information is not available to a people with complex communication needs unless they can access the Internet privately or are connected with professionals, such as Occupational Therapists, Physiotherapists or counsellors with expertise in sexuality and disability. This knowledge, at the time, might have assisted my sexual relationship to continue to develop. It is vital for young people with complex communication needs to have access to sex education which includes disability-specific information in order to develop healthy relationships.

To maintain healthy relationships and well-being, it is essential for people with complex communication needs to have access to relationship and sexual health services which go beyond the standard sex education (Collier et al., 2006). It is vital for these services to be available to all people with disabilities throughout their lives (World Health

Organization, 2011). However, even mainstream services are difficult to access as there are insufficient staff trained to understand and support the needs of people with complex communication needs (Collier et al., 2006; Solarsh, 2012). There has been a call for this type of service for more than a decade. (Collier et al., 2006; Emens, 2009).

Partners can also benefit from access to information on sex and disability. Both Eve and Oscar expressed the need to ensure that their sexual partners were aware of the impact of their disability on their sexual activities. In a relationship that develops over time, people with complex communication needs would have time to ensure that their partners have the required information. Yet if, as in many of the experiences described, when relationships escalate quickly to being sexual, how does one provide the required information? Jasmine highlighted the issue that, due to her spasticity, she was not able to communicate, therefore it would be impossible for her, in the moment, to provide relevant information. Drawing on my own experience and observations of other people with disabilities, thought and planning must precede most activities.

Further research is required into the kind of education that could have equipped people with complex communication needs to develop the relationship further, knowing their physical capabilities, and that could have enhanced their sexual experience. This could also assist in investigating the most appropriate communication methods and vocabulary required to participate in their sexual activities. In situations such as the one in which I found myself in San Francisco, which could have escalated to having sex, there would have been a point where Anton, my support worker, would have had to leave to give me privacy. If I had trusted in spontaneity, it may have gone well for both for my partner and me. However, if I attempted to provide additional disability information, the process of trying to communicate could possibly have destroyed the mood, discouraging the moment, or, on the other hand, could have helped to intensify the experience. Additional research could investigate appropriate methods to impart this knowledge to partners. This raises interesting issues for most people with complex communication needs and for AAC practitioners and requires further research.

7.3.6 Participants' attitudes

Although environmental factors had a large influence on participants' pursuit for intimacy, their own personal attributes also influenced the development of their relationships. It cannot be ignored that people with complex communication needs, through their own attitudes, can create barriers to forming friendships or intimate relationships (Dattilo et al., 2008). Conversely, people's positive attitudes can help to facilitate such relationships. Although none of the participants directly discussed whether they believed their personal attitudes had affected their relationships, the findings show that those attitudes did have a significant impact on the success of their relationships. The ICF does not consider personal attributes as barriers or facilitators to social participation, perhaps because negative connotations placed on personal factors can lead to denial of services by *blaming the victim* for their flaws (Leonardi et al., 2016; Simeonsson et al., 2014). However, in the results, the *Personal attitudes and attributes* theme demonstrated that personal attributes such as resilience and determination were facilitators in the development of participants' romantic and sexual relationships.

One of the strongest qualities emerging from the findings was that of the resilience of the participants to keep striving to develop romantic or sexual relationships, despite the relentless ableist attitudes they encountered. Their resilience and determination were facilitators for their social participation and enabled them to push through failures in pursuit of their need for social interactions and intimacy. For example, they were determined to connect with potential partners, despite external ableist pressures, as Jasmine demonstrated in turning to online dating sites to mitigate unwanted interference. On reflection, a possible explanation for this strong determination could be the ongoing negativity and ableism they continually encounter, and one could argue that resilience is developed through these struggles (McRuer, 2010). Perhaps this is a reflection on the type of people who volunteered to be involved in this kind of project. Yet could it also be a reflection on the type of characteristics that are developed through the continuous resistance to ableist attitudes encountered by people with complex communication needs? The constant pressure to conform to the expectations of others—parents, friends, colleagues and strangers—could have had an impact on the development of the resilience of participants.

I only recognised the participants' resilience as a key feature after discussions with several people, all independently of each another. After reading drafts of the results, all mentioned having a sense that each participant had demonstrated remarkable resilience. I was not unaware of this resilience, but it is feasible that from my standpoint I simply saw it as a given and it took observers from outside the cohort to draw my attention to it. Once identified, the significance of attributes of resilience and determination was obvious.

To have positive personal attributes such as good self-esteem is important to the development of social relationships (K. Anderson et al., 2011; Rintala et al., 1997; Shuttleworth, 2000a). While all the participants showed strong social confidence and self-esteem with drive to socialise, the majority revealed how tenuous was this confidence. Jasmine showed self confidence in her life in general but when a man showed interest in her at a concert, self-doubt set in as she started to question his motivations. She seemed to ask why an able-bodied man would be interested in a woman with a disability. Similarly, Emma had a strong sense of self-worth and self-esteem but acknowledged there are times when she experienced self-doubt. This aligns with the findings of Rintala et al. (1997) that suggested the already low levels of self confidence in women with communication disabilities were exacerbated by their difficulties interacting in dating situations. Even though in 21st century Western culture women have been brought up to have an increased sense of self-worth and self-confidence, these female participants faced sexism, ableism and social barriers (Santos & Santos, 2018).

A strong sense of autonomy in the participants emerged from the findings. In many cases, it was the participant who had to initiate the relationship. Apart from identifying the support of family and friends, it is interesting that no one mentioned having things freely done for them. In most of the experiences discussed, the participants were the initiators within their relationships. Even when they had formed an intimate relationship, they still had to work additionally hard, placing trust not only in their partners but also people surrounding them. The balance they must maintain between being as independent as they can be and being sufficiently vulnerable for a relationship to develop may not be obvious from the results. From my standpoint, I can observe that several of the participants, especially the ones with a strong sense of autonomy, would have had experience of this dilemma. They rely heavily on their ability to communicate with a diverse group of people in their lives, which goes beyond basic communication and includes a wide variety of social interactions.

However, while displaying a strong sense of resilience, participants also discussed vulnerability. Sophie talked about her feeling of confidence as part of her university student community evaporating in a moment. Emma reported feeling vulnerable when people made fun of her by reading out, from the strips of paper that her AAC printed, her conversation with a potential partner. Furthermore, several female participants discussed their vulnerabilities while participating in sex, having to rely on the partners totally and being concerned at the risk in which they were placing themselves. Jasmine spoke graphically of her sexual experiences, not being able to communicate, putting trust in her partner to treat her appropriately while she was in such a vulnerable position. Oscar placed himself at risk when meeting potential partners. He demonstrated his drive to socialise and meet men within the gay scene. He spoke of being denied entry into clubs as security thought he was drunk, and of being turned away by potential sexual partners when they realised that he was disabled. Yet, he became wiser as time passed and adapted his strategies for meeting men. When Oscar arranged to meet up with date prospects from a gay website, instead of going to their place and risking rejection at their door because of their ableist attitudes, he would have them come to him.

In the first two cases, Sophie and Emma's vulnerabilities were emotional as they were responding to external events. They spoke of being confident within their interactions in their environments. Their vulnerability was brought about by their own reactions to external stimuli which made them realise they were powerless because of an element of their disabilities. In the next two cases, their vulnerability was also triggered by being powerless in the situation because of their disability, yet they allowed themselves to be at risk of physical danger while they were pursuing intimacy. Although their disability was an element in their vulnerability, the participants did not focus on their disability when discussing their relational or sexual experiences.

As discussed previously in the chapter, the constant immersion of disabled people in ableism can result in them internalising the ideology (McRuer, 2010). The effect of ableism on the relationship of the participants was explored as an external force created from the attitudes of others. The concept of the participants internalising these ableist attitudes, which can create additional self-imposed barriers, is evident in Sophie's reaction to her reflection in a window and Katie's nervousness when first being with an able-bodied man. Both were making ableist judgements which placed barriers in the way of forming relationships.

It is difficult to ascertain from the experiences shared to what extent personal attributes influenced the development of the romantic or sexual relationships of participants. The focus of the participants was predominantly on external factors, instead of personal attributes and their disabilities. This could be because the type of participants that the research attracted appear to be those who have or have learned the personality traits that resist the oppressive factors they encounter. The participants in this research seem to have learned to accept their disability to a point, and to realise that it is not useful to dwell on it as this can become a barrier in itself. This contrasts with the research on intimacy and people with bladder exstrophy (D. Anderson, Murray, & Hurrell, 2013), where participants tended to focus on their impairments. Bladder exstrophy is only noticeable in times of intimacy and is significantly less visible in public than a communication and physical disability. Therefore, it is possible that the disability of participants with complex communication needs has become part of their everyday life and their identity rather than something to be dwelt on.

Even though their disabilities were peripheral to much of the discussion in the interviews, participants did focus on the extra effort they made to be resourceful and to organise people around them in order to gain what they need. In her article on undertaking a PhD candidature while having a disability, Hannam-Swain (2018) argued that there are additional factors with which a person with a disability has to contend in the attempt to participate in the community. There are many similarities in the experiences of the participants' development of relationships and Hanna-Swain's commencement of her candidature, including supportive parents and the need to organise and coordinate personal care support surrounding the activity.

Support systems are provided to assist, but their rigid policies can create more barriers. In the movie *The Sessions* written and directed by Ben Lewin (2012), the character O'Brien had polio. He was heavily reliant on his support workers to provide all of his personal care and had to be well-organised to ensure they met his needs. The results indicate that, like O'Brien, the participants had a strong drive to meet their sexual needs, and that they needed to be well organised to satisfy them. In both Katie's and Amelia's experiences, there was a need to negotiate with their support services in order to be able to participate in sexual activities. While this required them to be highly organised, this need for planning and structure can become a barrier to spontaneity, which is an important element of developing relationships.

A part of managing this balance within relationships, especially when meeting new people, includes providing some kind of what Oscar referred to as “disability awareness training”. On meeting new people, apart from the usual ritual of getting acquainted, there is another layer of complexity which relates to ableist attitudes that one must assist the other person to navigate. This is especially true when the person is unfamiliar with relating to a person with a disability. In my personal experience, one of the main ways a new friendship can fail is when the conversation becomes too focussed on disability and the person with the disability in a sense becomes a subject rather than an equal partner. Sometimes, the challenge is to maintain the balance, and this can be especially difficult with a communication disability.

This is one of the reasons that having a friend actively introduce a person who has complex communication needs to new people can assist. Ben specifically talked about an issue that was evident in many of the interviews: the need to be mindful of the additional effort required by the partner. This is an important factor that may not be well understood. Failing to do so could lead to the partner being burned out. However, overemphasising this could lead to the person with complex communication needs becoming subservient and losing their autonomy in the relationship.

7.4 Summary

The experiences of the participants demonstrated a similar range of sexualities and needs to the broader population and an ability to develop and maintain intimate relationships. The findings illuminated the additional barriers that the participants faced in this endeavour and the facilitators that helped advance their relationships. It was often supportive family members, friends and support workers who were significant facilitators in the social interactions and love lives of people with complex communication needs. While support workers play an important role as facilitators in client's personal lives, the policies that govern their practice often embody ableist attitudes, which can seriously hinder opportunities to have quality time with intimate partners. AAC devices can be useful in social situations but can be problematic in intimate settings. The participants' lack of access to appropriate sex education at high school was a hindrance to their sexual development and activity. Ableism featured prominently among the barriers which appeared in the attitudes of others, and even of the participants themselves. They did not dwell on their disabilities, despite the relentless ableism they encountered. Their resilience and determination were their strongest facilitators.

7.5 Implications of study findings

Even though the findings are from nine participants with complex communication needs, the outcomes provide an emerging evidence-base that may have implications for policy, theory, and the practices of various professionals and stakeholders.

7.5.1 Policy

At present there is a grey area in policy about provision of the support required by people with complex communication needs in expressing their sexuality and participating in intimate adult relationships. The disability sector needs to improve the development of policies governing the provision of personal care support in sexual activity, at both government legislation and support agency levels. Evidence in my research suggests that people with complex communication needs experience difficulty in navigating the type of support they require and are entitled to expect. This was demonstrated in Katie's experiences of having to negotiate with staff and agency policies to have physical time outside of their wheelchairs with her fiancé.

The recent introduction of the NDIS legislation in Australia aims to enable people to live a regular life by providing what is deemed to be reasonable and necessary care and support (Foster et al., 2016). The legislation is based on the ICF model which focuses on ten domains, one of which is interpersonal interactions and relationships (Mason, Crowson, Katsikitis, & Moodie, 2018), and this seems not to get the reasonable and necessary status it deserves. As research by Foster et al. (2016) has demonstrated, the NDIS guidelines and their implementation are ambiguous, but I believe it is important for the NDIS to have clear policies, especially around support for relationships and sexual activity. To ensure that the lives of people with disabilities in Australia are supported adequately, Mason et al. (2018) highlighted the need for research to support ongoing national policy development as the scheme is rolled out.

One vital area in need of research is the types of support that are lacking in relation to the ICF interpersonal interaction and relationships domain. This research highlights that people with complex communication needs, despite being supported in areas like daily living and education, still have to navigate their support systems, often outside of agency and government policies, to gain the personal assistance needed to progress their romantic and sexual lives. However, policies surrounding interpersonal relationships are likely to remain a low priority. Although there may not be public support, as Shildrick (2009) would suggest, clear and supportive policies must be developed and promoted, focusing on supporting people in developing relationships.

The legislation has a strong influence on the type of support services that are administered, but because interpersonal relationships are seen as a low priority, the policies focusing regarding the type of assistance available for sexual activities remain ambivalent (Shildrick, 2009; Siebers, 2012). Service providers need to investigate ways to meet the support needs of their clients seeking to participate in sexual and intimate activities and develop clear policies, practices and training for support workers in supporting them with their sexual activities in order to mitigate potential risk to all parties.

7.5.2 Practice

The findings have potential implications for several particular areas of practice including support work, AAC practitioners, educators, AAC designers and operators of entertainment venues.

7.5.2.1 Support workers

The findings highlight that people with complex communication needs must negotiate with their support workers for the types of supports that the workers are willing to give around personal care and sexual activities. Once again, it was Katie who raised these difficulties as she sought support workers who were willing to assist her with personal care and enable her to undertake sexual activities with her partners. In addition to the policy limitations, support workers have to be comfortable and willing to provide this assistance.

As mentioned above, the policies addressing personal care providers frequently lack clarity. When people with disabilities need sexual support, it can cause difficulties for support workers who consider they are going beyond their job descriptions, feel personally vulnerable in assisting in such activities, or are unwilling to assist due to personal beliefs. The people with the disability are also placed in a vulnerable position, having personal needs and desires that may jeopardise the working relationships, not to mention unwittingly acting against the policies of their service provider. An independent online solution should consider minimising the uncertainty and risks faced by these three stakeholders.

I propose a web-based application to be developed to assist people with complex communication needs, as well as people with other disabilities, in negotiating for support that may be considered as on the fringes of policy and practice. The online application could present users with a range of activities in a hierarchical structure, allowing for drilling down to more specific activities. Using a Likert-type scale, people could indicate the type of sexual activities for which they seek assistance, and the extent to which they desire such assistance. Workers could specify the type of assistance they are prepared to give, and service providers could specify the types of assistance their policies encompass. This information could be presented to the person with the disability and service provider in such a way as to keep confidentiality, enabling people to approach sensitive topics of support of a sexual nature more easily and with less vulnerability than currently exists. Obviously, this concept needs more thought and planning to reach implementation. Nevertheless, it has the potential to assist people with complex communication needs, and other disabilities, to communicate with confidence when negotiating for assistance with sexual activities.

However, I have noticed from my own experience over several decades in using support workers for personal care support, that training can influence the willingness of support workers to assist with sexual activities. Although the personal lived experiences and beliefs of the support workers play a major part in this willingness, those who tend to be open to providing such assistance were those whose training provider gave at least one session on sexualities of people with disabilities and explained that part of their role as support workers may involve assisting with sexual activities.

7.5.2.2 Practitioners

An AAC practitioner is a therapist, commonly a speech pathologist or an occupational therapist, who specialises in the AAC field. As members of an inter-disciplinary team, these practitioners conduct assessments in consultation with the person with complex communication needs (Beukelman & Mirenda, 2013). These assessments enable practitioners to recommend interventions, based on evidence-based practice, to assist the person with complex communication needs to achieve efficient outcomes and, in most cases, implement the interventions (Schlosser and Raghavendra, 2004).

It is important that AAC practitioners focus on building communication and language skills to enhance the participation of people with complex communication needs in all life domains. They need to take a whole life approach, ensuring the person has access to appropriate vocabulary and the opportunity to use that vocabulary. This includes vocabulary which supports sexual education and individual sexual expression. It is vital that the young person has access to adequate vocabulary to communicate with the adults around them and with their peer group. It is probable that two vocabulary sets would be different, as the type of language for the latter group would be less formal and more colloquial than the first. Nevertheless, this is important as it supports their social participation and development.

Practitioners must consider the support required by parents as part of delivering whole of life interventions. Parents play key roles in the lives of young people. Practitioners must offer guidance to parents, supporting young people, assisting them to understand that their child will develop sexuality. The realisation that their child is a sexual being who will experience similar developmental changes to their able-bodied peers, can be daunting for parents. This was apparent in the example I gave about the parent who realised for the first time when hearing my conference presentation that her child with complex communication needs was a person who would develop sexual feelings and needs. Therefore, it is important for teachers, therapists and AAC practitioners to be prepared to provide guidance to parents about their children’s sexual development.

The findings provide evidence that people with complex communication needs require AAC solutions enabling them to communicate in a variety of settings, and therefore, to be flexible. This may mean the need for more than one solution, with options for multi-modal communication depending on the situation. This includes intimate and sexual moments in which both enjoyment and safety are possible. This need was highlighted in the sexual experiences of Katie, Jasmine and Samuel, who all spoke to this issue. Creating AAC solutions for emerging and mature adults clearly requires creativity, thinking outside traditional therapy models.

The participants in this research revealed their innovative ability to improvising their own modes of communication when having sex. This demonstrates that the knowledge and expertise of people with complex communication needs should be fostered and included in the co-design and development of interventions. This will also assist them to further their knowledge and problem-solving skills, equipping them better for future endeavours when they will need to devise other communication modes.

7.5.2.3 Educators

This research suggests that school students do not receive adequate sexual health and relationship education at school, and is in agreement with Fader et al. (2011) that education and support must start early in a child's life. Both Samuel and Jasmine reported their belief that they did not receive adequate sex education. As with all developing adolescents, children with complex communication needs experience the usual physical, social and emotional changes. However, their disabilities mean that they need more resources than typical adolescents through these challenging times of growth and transition.

It is vital for young people with complex communication needs to have appropriate support around them, both at home and at school. Students have an inherent right under the Convention on the Rights of Persons with Disabilities to receive appropriate support in school (Article 24, United Nations, 2006). This needs to go beyond academic support, to include support in developing social relationships in and beyond the schoolyard. The type of education that would assist people with complex communication needs to develop relationships could include more emphasis on developing social enquiry etiquette, ableism awareness and management, and sex education with an added focus on their disability.

This access to sex education was an issue which many participants highlighted in their responses, together with the need for additional sexual information relating to their disabilities. It has been suggested that, within mainstream sex education, information could also be included regarding alternative sexual expressions and practices that could be employed by people with disabilities. Teachers must be supported by the provision of adequate material to provide comprehensive sex education for students with complex communication needs. This would also include exploring communication strategies for safe sexual practices.

The need for this type of sex education and sexual health information was identified by the participants as necessary and important for adults with complex communication needs. People with disabilities, their partners and families often lack access to education surrounding dating and sexuality, especially specific to their disability. An international website, driven by researchers, is needed to provide general sexual health information, and disability specific information. Disability professionals, service providers and members of the disability community could contribute to research that would be published on the site. Outcomes from this research could further inform and develop the educational content of the website. The website could also host online communities of people with disabilities and foster conversations on dating and sexuality. Such a research-based website would be a viable commercial opportunity for a university. As an educational internet site, it could provide only evidence-based disability-specific sexuality information to people with disabilities and their supporters but it could become an international research site identifying unmet need and stimulating further research.

Students and adults with complex communication needs could benefit from learning formally about ableism. Most participants demonstrated being skilled in dealing with ableist attitudes, but receiving formal education on ableism could further assist them in social networking and developing relationships. Such education would have modules on ableist attitudes, including a history of the disability movement to provide a context for improved understanding of the phenomenon of ableism. This would assist in the ready recognition of ableist attitudes and the development of strategies to deal with them.

7.5.2.4 AAC designers, engineers and suppliers

Participants indicated that their AAC devices did not adequately support their communication in socialising, let alone during love making. Within the AAC industry, as most designers, manufacturers and suppliers are able-bodied, it could be argued their devices are limited by ableist attitudes. However unintentionally, they limit the participation of people who use their technologies. AAC manufacturers and suppliers actively encourage users of communication devices to have input into product design, but there are complex issues surrounding accessibility, positioning and the need for flexibility. Despite this attempt to be inclusive, proposed solutions are generally filtered through able-bodied persons who ultimately decide what is produced.

It is clear that the design of current AAC devices created barriers for the nine participants in terms of developing relationships, from meeting new people to going to bed with partners. New wearable technology is being explored in the assistive technology field for people with disabilities (Mulfari, Minnolo, & Puliafito, 2017), and this could create opportunities for solutions that assist people with complex communication needs to converse with their partners while having sex. The AAC industry needs to realise the importance of these limitations and the potential market available.

7.5.2.5 Entertainment venues

Emma alluded to the difficulties of using her AAC device while at dinner parties due to the limited table place for it to be accessible, highlighting the importance of restaurants and cafes being not only physically accessible but also communication accessible. Ballin and

Balandin (2007) stated that public venues such as bars and restaurants are places where relationships develop but for people with complex communication needs these venues can be extremely difficult for them to participate socially. There have been numerous occasions when I have looked forward to going to dinner with friends as an opportunity to build relationships, only to find the venue too noisy to communicate, and leaving me to sit and listen to others for the whole evening. As higher education institutions are required to ensure programs, web presences and physical buildings are designed to accommodate a broad range of people (Brabazon, 2015), there should also be a requirement for entertainment venues to employ universal design. The Communication Access Network, in Victoria, Australia, provides disability and communication awareness training to business, promoting community inclusion for people with complex communication needs (Solarsh & Johnson, 2017). There is scope for such awareness programs to be endorsed and funded by government and targeted at entertainment venues nationally.

7.5.3 Theory

This research proposes that Feminist Standpoint Theory could be a useful research methodology to use in AAC research when one of the researchers has complex communication needs. It has been common practice within AAC research to have at least one such researcher contribute their lived experience. It is also a requirement that care is taken to ensure that this position is not tokenistic, and that the person has skills to contribute specifically in design and analysis of data. Usually no theoretical framework is used formally to maximise the researcher's standpoint. As discussed in the Theoretical Framework Chapter, this research has used a key feature of Feminist Standpoint Theory, that the researcher has the perspective of an outsider researcher and that of an insider—the concept of "the outsider within" (Collins, 1986).

Using Feminist Standpoint Theory within this project was not always straightforward and at times created robust debate between my supervisors and me. Although I respected their research and disability knowledge, there were times when I became frustrated because my perspective was different from theirs. The methodology or the interpretation of the data they proposed at times differed from mine. Researching Feminist Standpoint Theory helped me to understand what was happening within my meetings with my supervisors. I started to understand the concept of the 'insider researcher' and the power structures in which I found myself. I could acknowledge the academic expectations that were being placed on me and the power I wielded as an academic researcher, yet I recognised the traditional hierarchical oppression experienced by people with complex communication needs. Suddenly, I could understand the frustration I experienced at times in meetings. I was, in a sense, disrupting power structures that existed without my supervisors and me recognising them. I found myself having to devise methods of respectfully assisting them to understand my point of view, both with regard to the issue of the methodology or the interpretation of the data being discussed, and with the standpoint position that I found myself in as *the outsider within* (Collins, 1986). This experience deepened my knowledge of conducting AAC research as a researcher with complex communication needs.

I would recommend that when one of the researchers has complex communication needs, Feminist Standpoint Theory be used to provide a theoretical framework that allows the person with complex communication needs to utilise their own experience and their inside knowledge of the cohort. Other researchers need to understand Feminist Standpoint Theory. They need to acknowledge the unique methodological position of the researcher with complex communication needs and that extra time will be needed to understand the generated knowledge contributed by the insider researcher.

The voices of people with complex communication needs are easily lost within the broader Disability field, with their particular needs being ignored as others' needs are more easily heard. The research brings to the academic field the perspective of members of a cohort who are rarely heard, on a topic that is equally silent—romantic and sexual relationships. Nine participants with complex communication needs communicated boldly and clearly their desires, success and struggles with developing relationships. This gives the AAC field and broader Disability field new insights into the lived experiences of people with congenital physical and communication disability on a topic which revealed the depth of ableism encountered by them.

7.6 Limitations

The research project has inherent limitations that need to be taken into consideration while interpreting the outcomes. Although there are benefits to using Feminist Standpoint Theory in the interview and data analysis phases, it is acknowledged that by its nature my standpoint also brings with it my own biases and prejudices. I have remained conscious of this risk. In the Methodology Chapter, I have detailed the methods used to ensure that the interpretation of the data was rigorous and credible in order to be able to contribute new and unique understanding and knowledge to the academic field. However, as I have used my own standpoint, my contribution will be different from another researcher's interpretation and knowledge generation, using another theoretical perspective.

7.6.1 Study population

This was exploratory research with a small number of participants, but it is qualitative research which allows lower numbers. As reported in the Results chapter, the dataset would have been enhanced if the original target of 20 people had been met. However, it might then have been too large to interpret and report reliably and in such depth, given the time constraints of the PhD candidature and my physical abilities. It must be acknowledged the participants and I were all from western countries which had developed services for people with disabilities, and all had white privilege. Despite the sample limitations, the findings have produced rich and unique insights into the lives of people with complex communication needs. The limited sample should not detract from these rare insights into their lived experiences.

7.6.2 Recruitment

As mentioned in discussing the results, it is difficult to assess whether the type of participants the project attracted was due to any one cause. It could have been a result of the recruitment methodology used, however all the participants were confident users of internet-based technologies and were independently minded. The fact that they were limited to face to face interviews, either locally or online via Skype, may have been a discouraging factor for others. Future research needs to investigate methods to reach others with complex communication needs who might not be as confident, to obtain a deeper understanding of their relationships desires and needs.

Ten participants were recruited; however, one decided to withdraw after the first interview session. Although he reported having read the recruitment information and understood the project, it seems that he expected that the issues he would cover would be less personal. Another possible complication could have been that he and I had a decade long friendship and he was not comfortable in talking about his partner who I knew as well.

Within the Disability field, the parents, support workers or guardians who protect and filter the information exchanged with the people they support feel an obligation to protect them, and for this reason, are known as gatekeepers (Darragh, Reynolds, Ellison, & Bellon, 2017; Olli, Vehkakoski, & Salanterä, 2012). The gatekeepers may believe that the person is not sufficiently mature to understand the topic. Alternatively, they may fear that it would expose the person to new ideas that the person might subsequently decide to pursue.

Therefore, gatekeepers limit the amount and the type of information that the person they support can receive or communicate. This also includes actively discouraging them from participation in research. As most people with complex communication needs are totally reliant on their support providers for all personal care, they have difficulty independently accessing and responding to information. There was no direct evidence that any of this occurred, yet, given the low response rate, I suspect that potentially eligible participants may had been prevented from expressing interest by gatekeepers.

A possible limitation, related to the recruitment process, was that potential participants may have found it daunting to be interviewed by someone unknown to them with complex communication needs. This may have been intensified by the personal and sensitive nature of the topic. Potential participants may have doubted the legitimacy of the project because it was being undertaken by a researcher from within the cohort. They may also have perceived that their experiences with relationships were too insignificant to be of research value. Any of these factors may have contributed to the low number of participants.

7.6.3 Study Design

Communication difficulties experienced by both the researcher and the participants meant the three-hour time limit for each interview was only enough to scratch the surface. In retrospect, it would have been preferable to have structured three to four three-hour sessions over a six-month period. These sessions could have been conducted over several time slots in close sequence, allowing me to conduct, transcribe, obtain confirmation and analyse the data to plan for the next interview. Subsequent interviews could have been used to clarify understanding and delve more deeply into the experiences shared by participants. Gaining a fuller understanding would take more time and effort.

Care must also be taken in interpreting the findings, as the data may not be representative due to the small number of participants. Small scale qualitative research such as this is useful in understanding phenomena which are little known, but to confirm the findings, large scale quantitative research is needed (Jonason & Balzarini, 2016). Any generalisations should be made carefully.

7.7 Future research

As this was an exploratory research study that began an important conversation in the Disability field, and specifically in the AAC field, the research has raised more questions that demand further research. This research has highlighted that it is vital to take a holistic approach when implementing AAC interventions in romantic and sexual relationships. This is fundamental in ensuring people with complex communication needs can enjoy their UNCRPD enshrined rights that have been adopted by Australia and other signatory nations.

7.7.1 Sex, relationship and disability education

Evidence in this research reveals people with complex communication needs frequently are excluded from formal sex education in schools and from vital conversations with their peers. Participants reported wanting additional information beyond the usual sex education offered in mainstream schools. They sought specific information pertaining to the impact of their disability on their ability to have sex. Research is required into the range of topics that could be included in sex and relationship education, to better equip people with complex communication needs to develop intimate relationships. The research could also investigate the most appropriate communication methods and vocabulary required to participate in their sexual activities.

7.7.2 Communication methods for safe, enjoyable and consensual sex

Communication is a major element within the practice of the BDSM community as it is vital for participants to be able to communicate their expectations, wants and preferences during participation, as well as before the activities (Tellier, 2017). Tellier (2017) suggests the disability community could learn from this open and honest communication between participating partners. In BDSM activities that involve mouth gags or facial masks, communication is restricted for at least one of the participants, and the other has power over the activities, yet communication is maintained throughout the acts. This has similarities to some experiences discussed in this research, where the participants enjoyed having sex but had very limited or no communication. Research could investigate which BDSM communication strategies could be adapted to be effective AAC strategies in order to ensure safe, enjoyable and consensual sexual activities.

7.7.3 Communication strategies for interactions with potential partners

As several participants mentioned, on meeting a potential romantic or sexual partner, it can be difficult to know the most appropriate method of telling them about their disability, as this has the potential to negatively impact a budding relationship. For example, if a person with complex communication needs attempted to provide additional disability information at an inappropriate time, or in an inappropriate manner, this could impede an unfolding sexual experience. On the other hand, it could help to intensify the experience. Future research could investigate appropriate methods to impart this knowledge to potential partners. This kind of research could assist AAC practitioners to choose the type of communication strategies that they teach and assist AAC designers to improve the features they incorporate in systems.

This research found that the use of online dating sites was one of the identified facilitators in finding potential partners. The issue of disclosing a disability was raised by all of the participants using these sites. Further research is recommended to investigate the online dating experience of people with complex communication needs, to identify the effective communication strategies they use on these sites to connect with others and best practice in disclosing their disability.

7.7.4 Design specifications for effective AAC

Further research is needed into the design of AAC systems that are effective for intimate communication. The research revealed that participants were not able to access their AAC devices in intimate moments. Some indicated that they relied on their partners to maintain communication while having sex. Human interface design research is needed to inform AAC design so as to improve intimate communication. Such research could assist in producing innovative solutions to exploit the market potential identified in Implications (see section 7.5.2.4). This should include research into using wearable technological solutions for people with disabilities, building on the research being conducted by Mulfari et al. (2017).

7.7.5 Engaging people with complex communication needs in sensitive research

This ambitious research successfully investigated a sensitive topic with people who have complex communication needs. There was very little literature found on this issue within the AAC field. Despite the recruitment limitations and the difficulties related to both participants and researcher having complex communication needs, this research has demonstrated that deep understanding and knowledge can be generated about the lives of people with complex communication needs. However, further research is needed into ways of encouraging and engaging people with complex communication needs to participate in such research.

7.7.6 Longitudinal research into relationship development

The findings revealed that participants referred to their circle of friends in many of their experiences and reported attending social events. They identified that friends acted as facilitators, supporting them in their romantic endeavours. However, none of them spoke specifically of particular friendships. Therefore, it was difficult to ascertain the quality and quantity of the friendships, or the opportunities they had to meet new people, an important aspect of meeting potential partners. Exploring the development of friendships could be the subject of longitudinal research in the future.

7.7.7 Support required for diverse sexualities

The prevalence of people with cerebral palsy with diverse sexualities was raised by two participants (see section 7.3.1.4). Further research is required into the support needed for people in this cohort, such as additional information on alternative sexuality and support required to enable people to participate in their chosen sexual activities. The research could assist to improve the information available within sex education for young people, and to enhance the training provided to support workers who may work for people with diverse sexualities.

8 Conclusion

This was an exploratory project investigating the lived experience of people with physical and communication disabilities in developing romantic and sexual relationships. The research only scratched the surface, yet it shed a light on the lived experiences of people with complex communication needs in developing romantic or sexual relationships. It highlighted that for them to succeed they had to be organised and resourceful and they demonstrated this strongly.

Nine participants were interviewed regarding their lived experience of developing romantic and sexual relationships. The experiences of the participants demonstrated a similar range of sexualities and needs to the broader population and an ability to develop and maintain intimate relationships. Furthermore, they pursued these relationships with either able-bodied or disabled partners. They discussed a diverse range of experiences and their desire to be in adult relationships showed clearly through all their experiences. At the time of the interviews, only two were in romantic relationships and two were in sexual relationships.

In addition to the hindrances to relationship development that most people encounter, the participants reported they had extra issues which directly related to their disabilities. Although AAC devices were useful in social interactions, they did not adequately support the participants to engage in conversations, or were completely inaccessible, for example, when the participants were in bed. As a result of receiving poor sex education, or none at all, participants indicated their love making experiences were affected. Further, they said that they, and their partners, could benefit from having access to knowledge relating to the impact of their disability on their sex lives. However, the majority of the barriers participants encountered were consequential of ableist attitudes they experienced from acquaintances and strangers, as well as people close to them—family members, friends and workers.

The prevalence of ableism was evident in many of their experiences of attempting to develop adult relationships. This included attitudes which prevented entry to nightclubs, over-protective parents and friends, and exclusion from sex education. One subtle but destructive manifestation of ableism is a phenomenon I identified and called “the invisible line,” which was evident in the experiences of two participants. The people with the disability believed they were behaving within social norms, when they experienced sudden disapproval from their friends. This negative response which affected all parties was not comprehended by the people involved. For the person with a disability, the response implied that a different set of standards was being applied to them and hence their relationships were hindered by this manifestation.

It was often the positive attitudes and support of family members, friends and support workers which were significant facilitators in the social interactions and love lives of people with complex communication needs. The participants had developed strategies to counteract the ableism they faced. Having friends introduce them by providing some additional information about their modes of communication and potential common interests, increased opportunities to form friendships by providing additional scaffolding to support conversations. A second strategy was to use online dating services to meet potential partners. This allowed for a degree of anonymity and control over deciding when and how to disclose one’s disability.

A key feature of this project was that both the researcher and all participants had complex communication needs which necessitated incorporating additional methodological considerations in the design. My status as a researcher with situated knowledge has assisted in producing rich and unique insights into the lives of people with complex communication needs. The personal and sensitive topic of the research could have been a contributing factor to the small sample size, but this should not detract from these rare insights.

This research has contributed knowledge and insight which can help advance evidence-based interventions and AAC technology. It has facilitated a much-needed conversation within the field of AAC, and the broader Disability field, regarding intimacy and adult relationships. It has pointed out limitations which need to be addressed and proposed that further research and development is necessary into AAC strategies and devices to support intimate conversation, especially in bed. It also proposed that personal care providers need to investigate the best practices for supporting their clients seeking to participate in sexual and intimate activities, and that further attention is needed in the areas of sex and relationships education.

Throughout the project, a sense of purpose and a pioneering spirit were noted in the responses of all the participants. Despite the relentless ableist attitudes they encountered, they generally did not focus on their disabilities as inhibitors, and their most influential facilitators were their resilience and determination.

Epilogue

A scholar who was disabled himself, Oliver (1996) argued social research must have benefits to the participants themselves. So, I thought it was important to inform the participants of the research and others with complex communication needs about some of the major outcomes. To the nine participants, I was honoured by the keenness you all showed in giving me an opportunity to discuss your personal and sensitive information while living with complex communication needs.

In the Discussion chapter, I proposed that the reason that you displayed resilience and determination through the experiences shared could be because of the ableism that you were bombarded with daily. The constant ableism you faced made you stronger. The source of it appeared to be not only from the general public but also from people within your support groups, professionals, teachers and parents. It is their attitudes which often limited your opportunities to form romantic and sexual relationships. Through this I have gained insight into the importance of people with disabilities being able to identify and subvert the ableism they encounter. Although many of you navigated the ableism successfully, the findings highlighted the need people with complex communication needs had for education to gain the skills to recognise ableism and mitigate its effects.

A key finding which could arguably assist people with complex communication needs, is that it could be useful to allow friends to provide more information when introducing you to new people, rather than simply exchanging names. With your permission, they could introduce you by giving the other person more information, such as your interests and the way you communicate. This could provide a stronger foundation for friendship and possibly a relationship to form. However, the strong message that came through all of the interviews was the idea that you were all satisfied with your own sexuality, and you were willing to advocate for the support you needed, be it educating your potential partner about your disability or organising personal care support.

Many of the findings of the research will possibly not be surprising, but I hope you gain new insights which could be useful in your romantic and sexual lives. In starting this project, I was hoping that one of the chapters of this thesis would be devoted to useful information on making new friends, developing relationships past the friendship and enhancing lovemaking. My assumption was that the emphasis would be more about the things that we can do to enter a relationship. This is possibly a reflection of the messages we got as we were growing up with disabilities, which impressed on us the need to be independent and strong, the sense that it is up to us to make things happen. However, the findings give a slightly different picture that could make us change our thoughts. Each of you as participants showed extreme levels of resilience and were successful in developing relationships. Faced with the usual struggles of developing relationships, you encountered additional barriers to most, and demonstrated your determination by using alternative methods to achieve the outcomes you desired.

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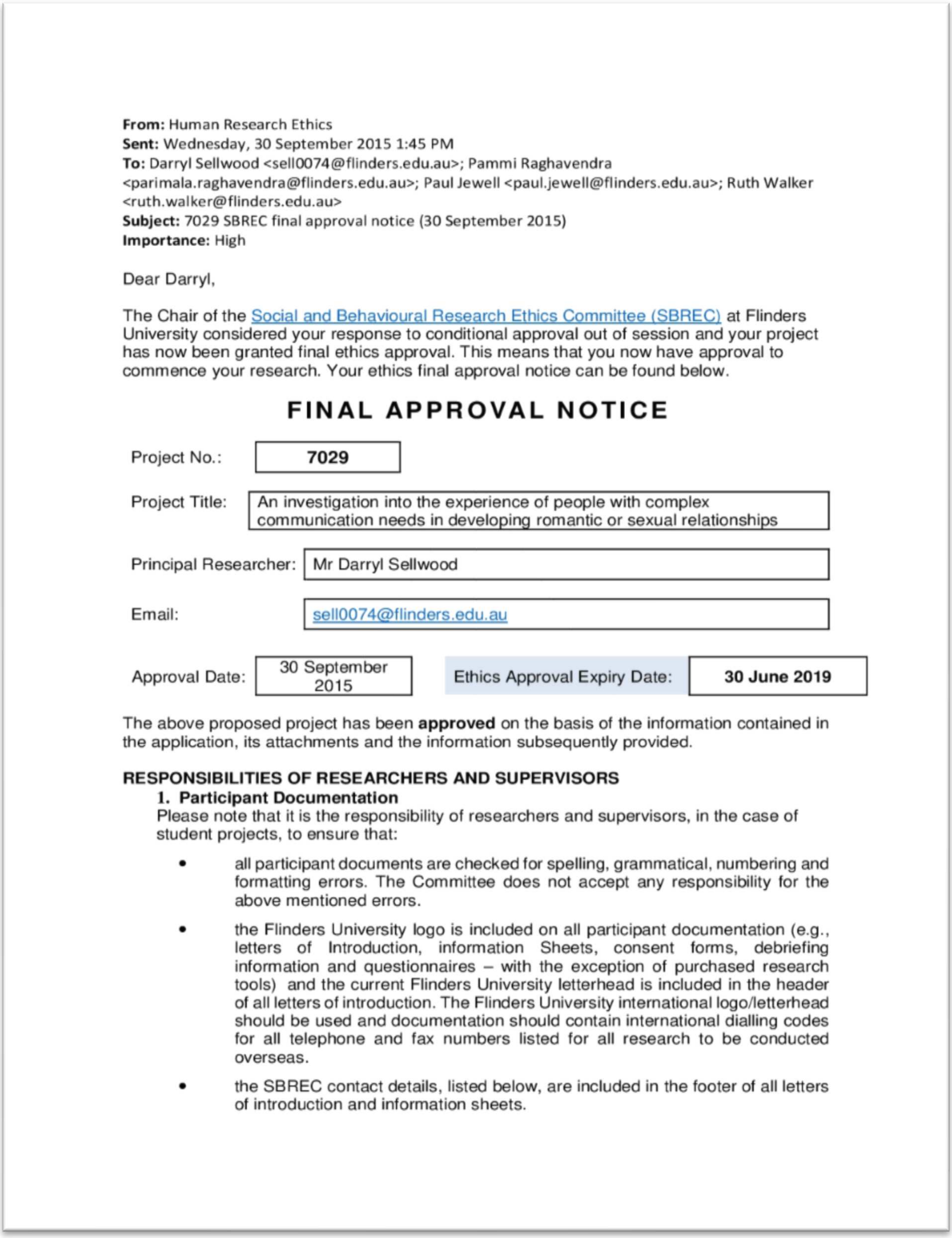
Appendices

Appendix 1. Ethics Approval Letter



From: Human Research Ethics
Sent: Wednesday, 30 September 2015 1:45 PM
To: Darryl Sellwood <sell0074@flinders.edu.au>; Pammi Raghavendra <parimala.raghavendra@flinders.edu.au>; Paul Jewell <paul.jewell@flinders.edu.au>; Ruth Walker <ruth.walker@flinders.edu.au>
Subject: 7029 SBREC final approval notice (30 September 2015)
Importance: High

Dear Darryl,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.: **7029**

Project Title: An investigation into the experience of people with complex communication needs in developing romantic or sexual relationships

Principal Researcher: Mr Darryl Sellwood

Email: sell0074@flinders.edu.au

Approval Date: 30 September 2015

Ethics Approval Expiry Date: **30 June 2019**

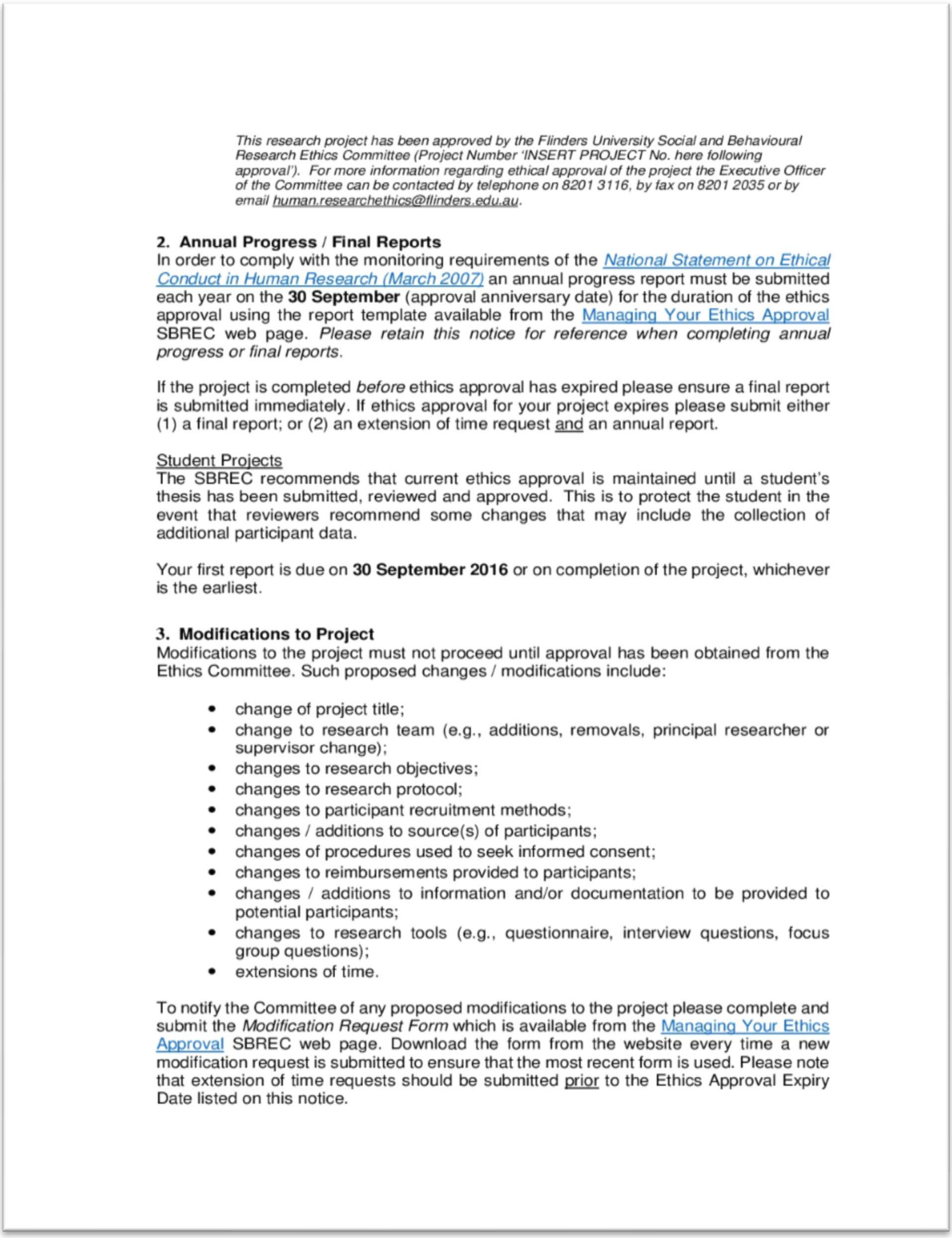
The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.



This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **30 September** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

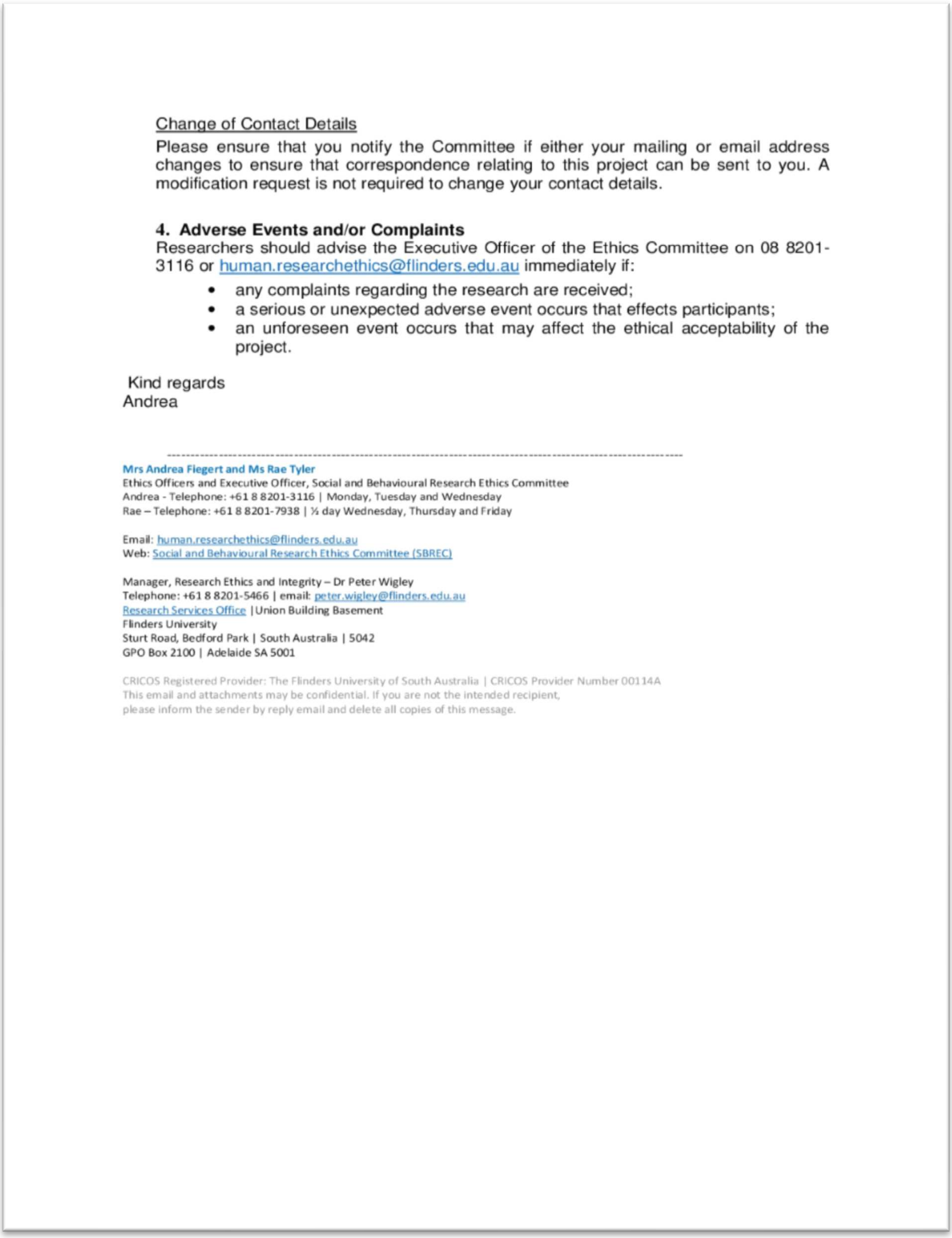
Your first report is due on **30 September 2016** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.



Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Andrea

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au
Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

Appendix 2. Participant Letter of Introduction

Flinders
UNIVERSITY

School of Health Sciences
GPO Box 2100
Adelaide SA 5001

Tel: +61 (08) 8201 3426
Fax: +61 (08) 8201 3646

www. flinders.edu.au

CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

(for participants)

Date

To Participant

My name is Pammi Raghavendra. I am an Associate Professor in the Disability and Community Inclusion Unit (DCIU) in the School of Health Sciences at Flinders University in Adelaide. I would like to introduce you to Darryl Sellwood, a PhD student in the Disability and Community Inclusion Unit at the Flinders University.

He is undertaking research to write a thesis and other publications, such as journal articles, on the topic of the experiences of people with Complex Communication Needs in developing intimate sexual relationships. The research is investigating how people form and maintain romantic or sexual relationships when they have physical and communication disabilities from childhood. As a person who has cerebral palsy and uses an AAC device to assist him to communicate, Darryl understands many of the challenges people with Complex Communication Needs face in navigating relationships.

Darryl would like to invite you to assist with this project by agreeing to be involved in an interview about your experiences in developing romantic or sexual relationships. He will negotiate a time and place to suit you for the interview. This may occur either face to face or by Skype. The interview could take between one and three hours over a number of sessions to complete. You may choose to have a communication assistant of your choice, a person who you trust and is able to assist you with your communication, in the interview. You are free to discontinue participation at any time or to decline to answer particular questions.

To ensure your views are noted accurately, Darryl will seek your consent prior to the interview to make a video recording of the interview. One of Darryl's academic assistants will be present in the interview and will assist with the transcription of the recording. Both academic and communication assistants will be required to sign a confidentiality agreement to ensure any information provided, including your name and identity, will be treated in the strictest confidence. Be assured that any information provided will be treated in the strictest confidence and you will not be individually identifiable in the resulting thesis and any other publications.

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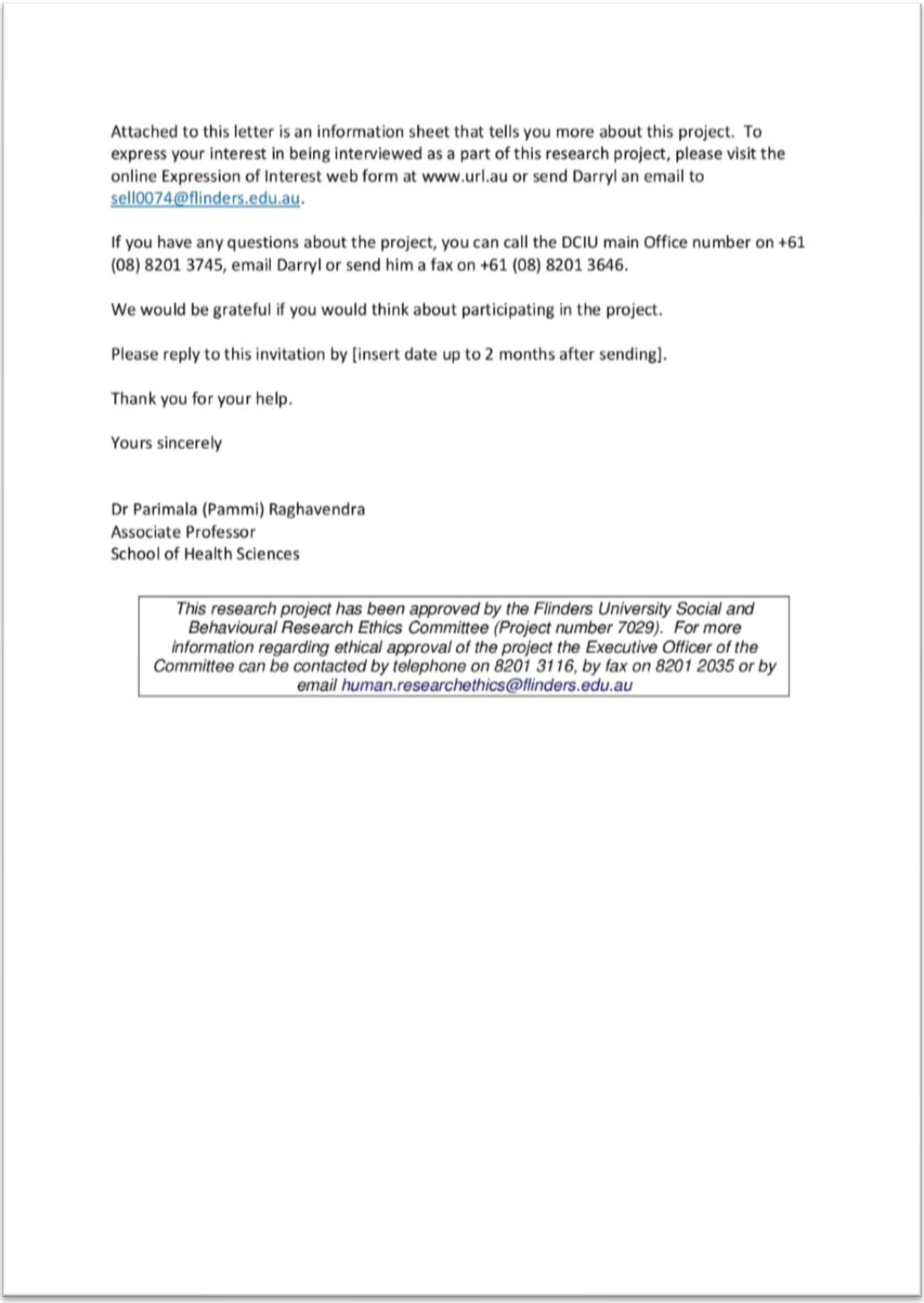
achievement



Attached to this letter is an information sheet that tells you more about this project. To express your interest in being interviewed as a part of this research project, please visit the online Expression of Interest web form at www.url.au or send Darryl an email to sell0074@flinders.edu.au.

If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email Darryl or send him a fax on +61 (08) 8201 3646.

We would be grateful if you would think about participating in the project.

Please reply to this invitation by [insert date up to 2 months after sending].

Thank you for your help.

Yours sincerely

Dr Parimala (Pammi) Raghavendra
Associate Professor
School of Health Sciences

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 3. Participant Information Sheet

Flinders
UNIVERSITY
ADELAIDE • AUSTRALIA

Mr Darryl Sellwood
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
Adelaide, South Australia, 5001
Ph: +61 8 8201 3745
Email sell0074@flinders.edu.au
CRICOS Provider No. 00114A

INFORMATION SHEET
(participants)

Title:

'An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships

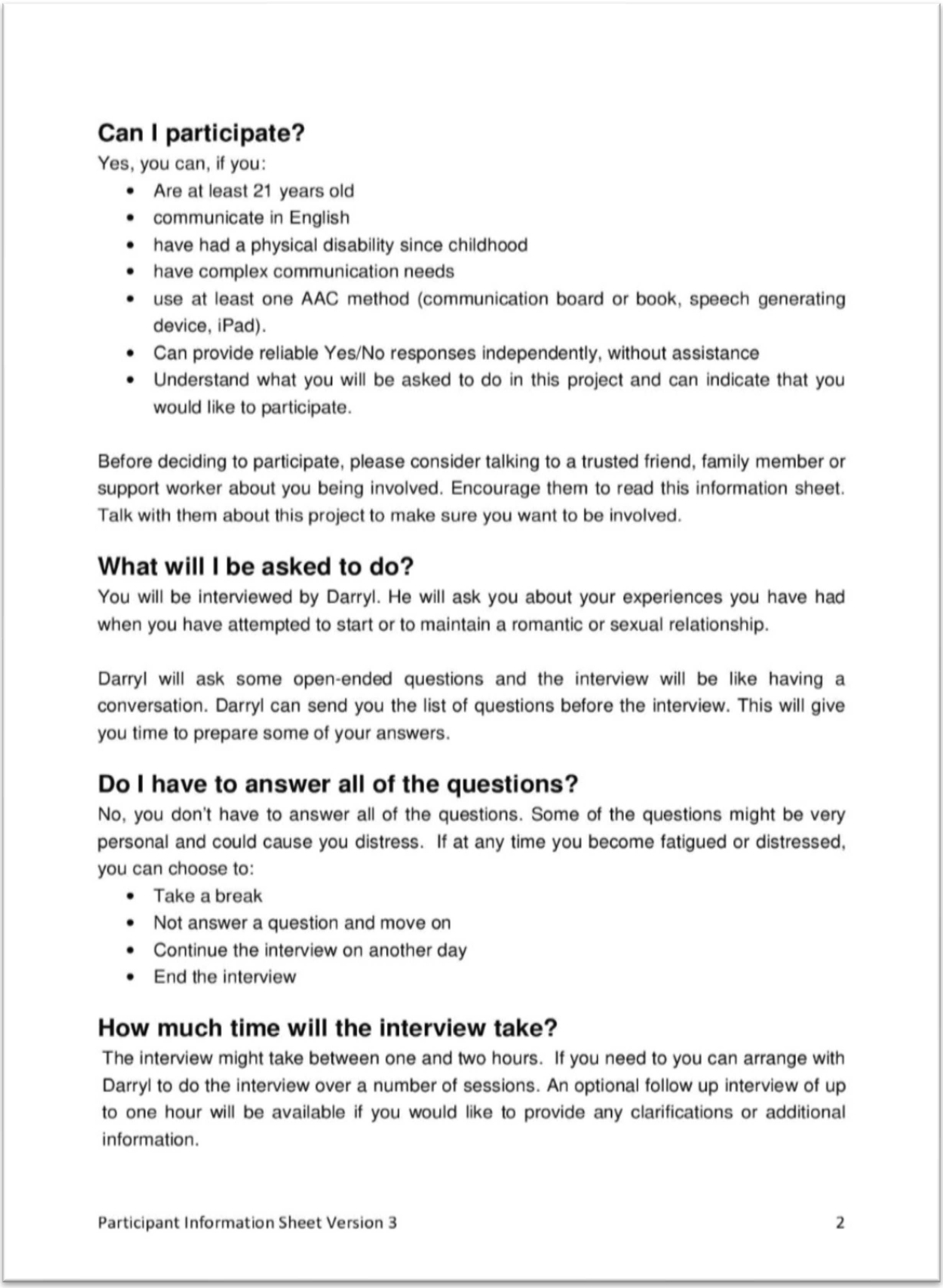
What is the study about?

This research project is supported by the Disability and Community Inclusion Unit (DCIU) of Flinders University. It investigates the experiences of people with Complex Communication Needs in getting into and keeping romantic or sexual relationships. This research is important because these people are rarely asked about and supported in their love lives. It explores very personal and sensitive issues which are not often discussed. Lovers with physical and communication disabilities receive little support in navigating relationships.

Darryl Sellwood, the researcher, understands many of the challenges people with Complex Communication Needs face as he has cerebral palsy and uses an AAC device to assist him to communicate. He will interview participants to explore their experiences with relationships. The things he discovers could help improve support to these people in order to have loving relationships with boyfriends, girlfriends, husbands and wives. From the information he collects in the interviews, Darryl will write a thesis for his PhD.

Participant Information Sheet Version 3

inspiring achievement



Can I participate?

Yes, you can, if you:

- Are at least 21 years old
- communicate in English
- have had a physical disability since childhood
- have complex communication needs
- use at least one AAC method (communication board or book, speech generating device, iPad).
- Can provide reliable Yes/No responses independently, without assistance
- Understand what you will be asked to do in this project and can indicate that you would like to participate.

Before deciding to participate, please consider talking to a trusted friend, family member or support worker about you being involved. Encourage them to read this information sheet. Talk with them about this project to make sure you want to be involved.

What will I be asked to do?

You will be interviewed by Darryl. He will ask you about your experiences you have had when you have attempted to start or to maintain a romantic or sexual relationship.

Darryl will ask some open-ended questions and the interview will be like having a conversation. Darryl can send you the list of questions before the interview. This will give you time to prepare some of your answers.

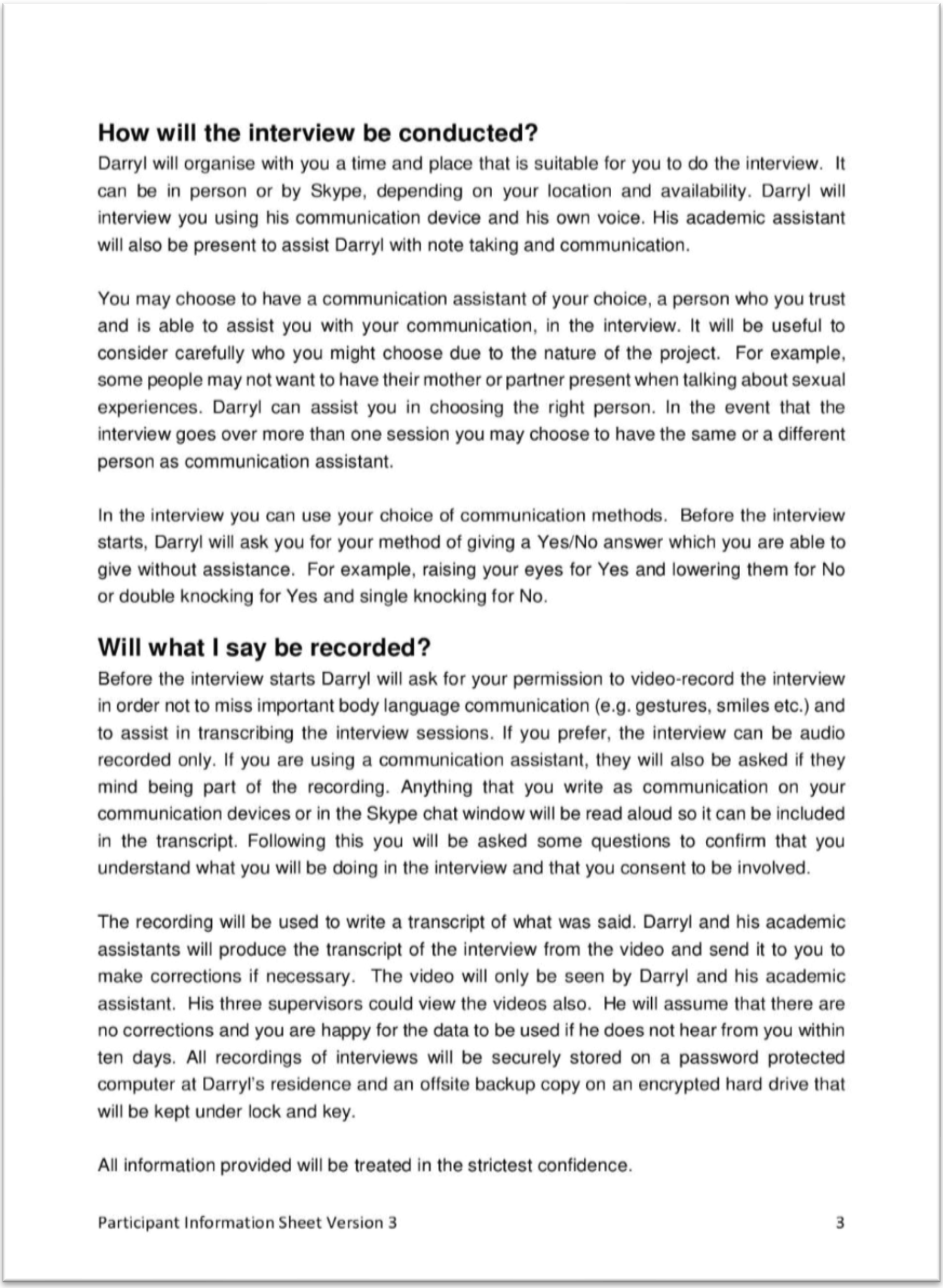
Do I have to answer all of the questions?

No, you don't have to answer all of the questions. Some of the questions might be very personal and could cause you distress. If at any time you become fatigued or distressed, you can choose to:

- Take a break
- Not answer a question and move on
- Continue the interview on another day
- End the interview

How much time will the interview take?

The interview might take between one and two hours. If you need to you can arrange with Darryl to do the interview over a number of sessions. An optional follow up interview of up to one hour will be available if you would like to provide any clarifications or additional information.



How will the interview be conducted?

Darryl will organise with you a time and place that is suitable for you to do the interview. It can be in person or by Skype, depending on your location and availability. Darryl will interview you using his communication device and his own voice. His academic assistant will also be present to assist Darryl with note taking and communication.

You may choose to have a communication assistant of your choice, a person who you trust and is able to assist you with your communication, in the interview. It will be useful to consider carefully who you might choose due to the nature of the project. For example, some people may not want to have their mother or partner present when talking about sexual experiences. Darryl can assist you in choosing the right person. In the event that the interview goes over more than one session you may choose to have the same or a different person as communication assistant.

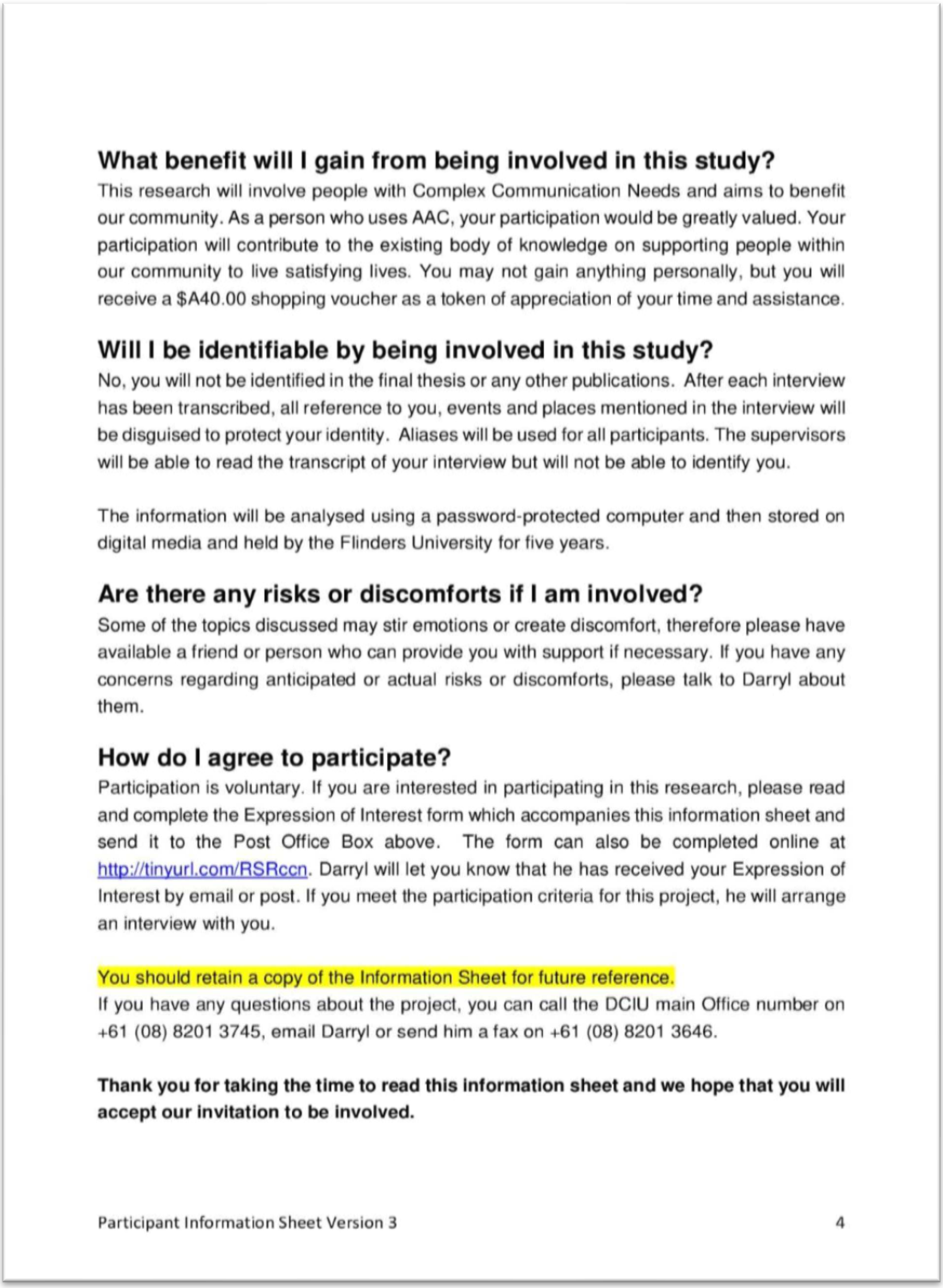
In the interview you can use your choice of communication methods. Before the interview starts, Darryl will ask you for your method of giving a Yes/No answer which you are able to give without assistance. For example, raising your eyes for Yes and lowering them for No or double knocking for Yes and single knocking for No.

Will what I say be recorded?

Before the interview starts Darryl will ask for your permission to video-record the interview in order not to miss important body language communication (e.g. gestures, smiles etc.) and to assist in transcribing the interview sessions. If you prefer, the interview can be audio recorded only. If you are using a communication assistant, they will also be asked if they mind being part of the recording. Anything that you write as communication on your communication devices or in the Skype chat window will be read aloud so it can be included in the transcript. Following this you will be asked some questions to confirm that you understand what you will be doing in the interview and that you consent to be involved.

The recording will be used to write a transcript of what was said. Darryl and his academic assistants will produce the transcript of the interview from the video and send it to you to make corrections if necessary. The video will only be seen by Darryl and his academic assistant. His three supervisors could view the videos also. He will assume that there are no corrections and you are happy for the data to be used if he does not hear from you within ten days. All recordings of interviews will be securely stored on a password protected computer at Darryl's residence and an offsite backup copy on an encrypted hard drive that will be kept under lock and key.

All information provided will be treated in the strictest confidence.



What benefit will I gain from being involved in this study?

This research will involve people with Complex Communication Needs and aims to benefit our community. As a person who uses AAC, your participation would be greatly valued. Your participation will contribute to the existing body of knowledge on supporting people within our community to live satisfying lives. You may not gain anything personally, but you will receive a $A40.00 shopping voucher as a token of appreciation of your time and assistance.

Will I be identifiable by being involved in this study?

No, you will not be identified in the final thesis or any other publications. After each interview has been transcribed, all reference to you, events and places mentioned in the interview will be disguised to protect your identity. Aliases will be used for all participants. The supervisors will be able to read the transcript of your interview but will not be able to identify you.

The information will be analysed using a password-protected computer and then stored on digital media and held by the Flinders University for five years.

Are there any risks or discomforts if I am involved?

Some of the topics discussed may stir emotions or create discomfort, therefore please have available a friend or person who can provide you with support if necessary. If you have any concerns regarding anticipated or actual risks or discomforts, please talk to Darryl about them.

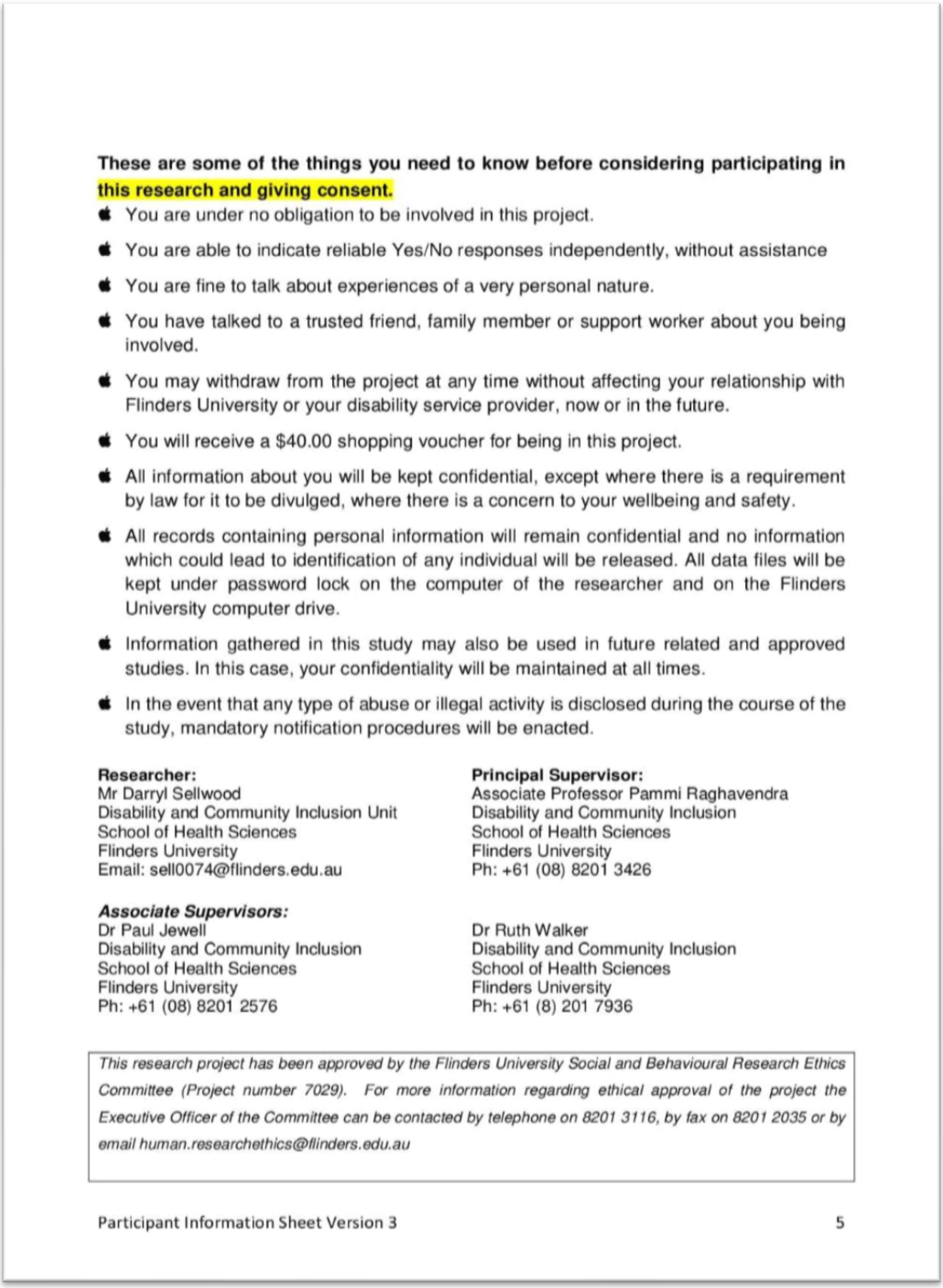
How do I agree to participate?

Participation is voluntary. If you are interested in participating in this research, please read and complete the Expression of Interest form which accompanies this information sheet and send it to the Post Office Box above. The form can also be completed online at http://tinyurl.com/RSRccn. Darryl will let you know that he has received your Expression of Interest by email or post. If you meet the participation criteria for this project, he will arrange an interview with you.

You should retain a copy of the Information Sheet for future reference.

If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email Darryl or send him a fax on +61 (08) 8201 3646.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.



These are some of the things you need to know before considering participating in this research and giving consent.

- You are under no obligation to be involved in this project.
- You are able to indicate reliable Yes/No responses independently, without assistance
- You are fine to talk about experiences of a very personal nature.
- You have talked to a trusted friend, family member or support worker about you being involved.
- You may withdraw from the project at any time without affecting your relationship with Flinders University or your disability service provider, now or in the future.
- You will receive a $40.00 shopping voucher for being in this project.
- All information about you will be kept confidential, except where there is a requirement by law for it to be divulged, where there is a concern to your wellbeing and safety.
- All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released. All data files will be kept under password lock on the computer of the researcher and on the Flinders University computer drive.
- Information gathered in this study may also be used in future related and approved studies. In this case, your confidentiality will be maintained at all times.
- In the event that any type of abuse or illegal activity is disclosed during the course of the study, mandatory notification procedures will be enacted.

Researcher:
Mr Darryl Sellwood
Disability and Community Inclusion Unit
School of Health Sciences
Flinders University
Email: sell0074@flinders.edu.au

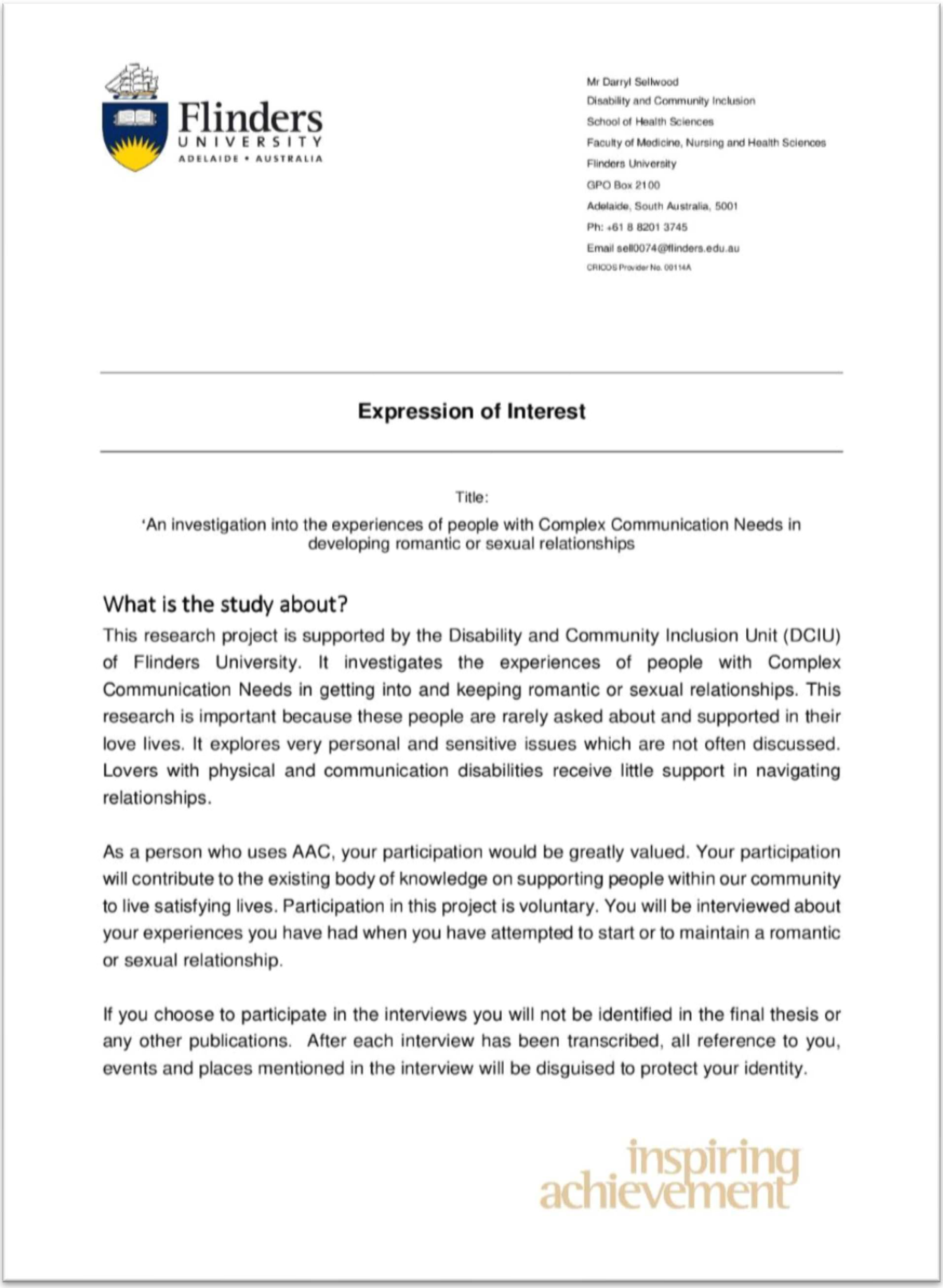
Principal Supervisor:
Associate Professor Pammi Raghavendra
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (08) 8201 3426

Associate Supervisors:
Dr Paul Jewell
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (08) 8201 2576

Dr Ruth Walker
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (8) 201 7936

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 4. Expression of Interest



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Mr Darryl Sellwood
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University
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Adelaide, South Australia, 5001
Ph: +61 8 8201 3745
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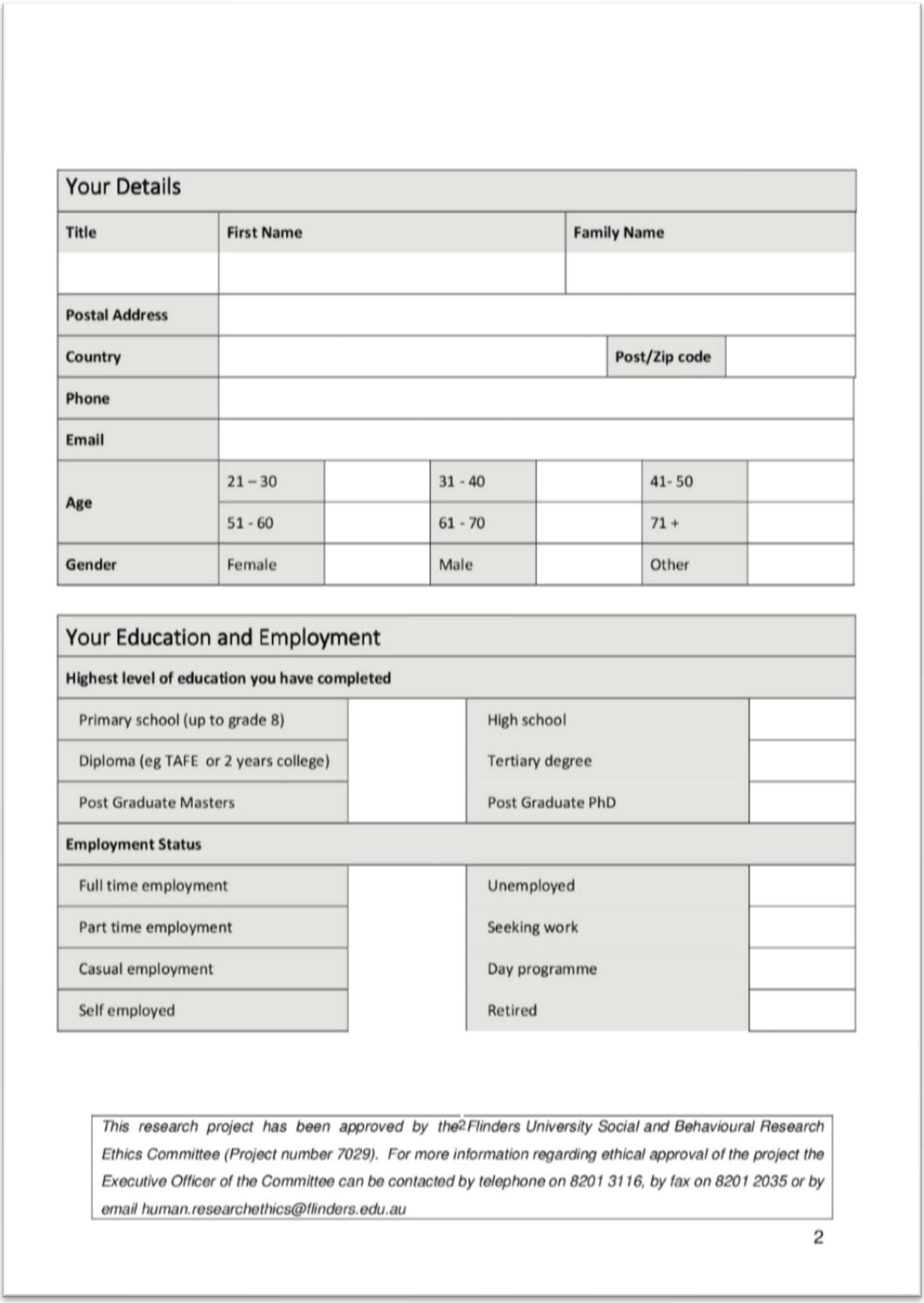
As a person who uses AAC, your participation would be greatly valued. Your participation will contribute to the existing body of knowledge on supporting people within our community to live satisfying lives. Participation in this project is voluntary. You will be interviewed about your experiences you have had when you have attempted to start or to maintain a romantic or sexual relationship.

If you choose to participate in the interviews you will not be identified in the final thesis or any other publications. After each interview has been transcribed, all reference to you, events and places mentioned in the interview will be disguised to protect your identity.

inspiring achievement



Your Details

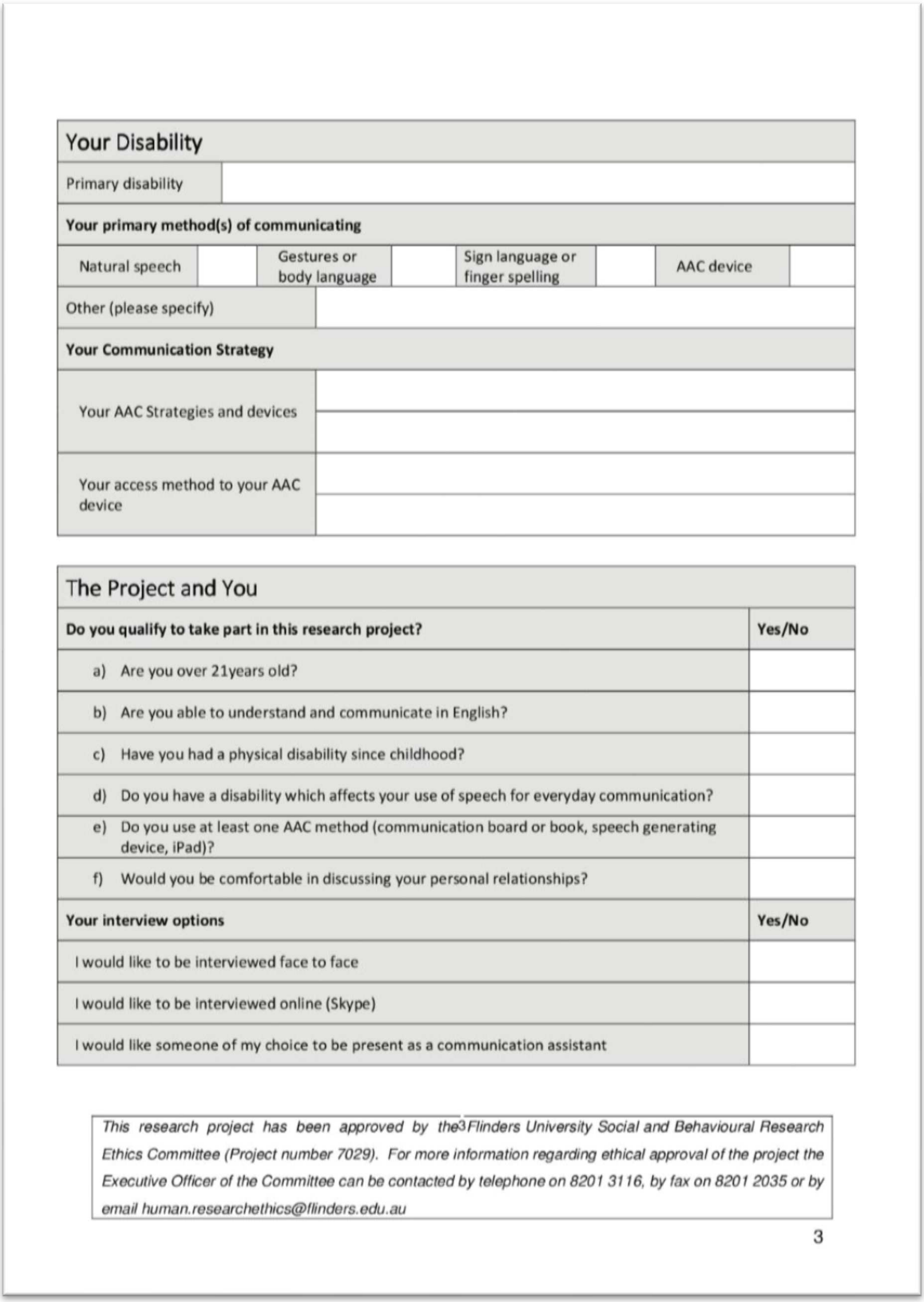
Title	**First Name**			**Family Name**		
Postal Address						
Country				**Post/Zip code**		
Phone						
Email						
Age	21 – 30		31 - 40		41- 50	
	51 - 60		61 - 70		71 +	
Gender	Female		Male		Other	

Your Education and Employment

Highest level of education you have completed			
Primary school (up to grade 8)		High school	
Diploma (eg TAFE or 2 years college)		Tertiary degree	
Post Graduate Masters		Post Graduate PhD	
Employment Status			
Full time employment		Unemployed	
Part time employment		Seeking work	
Casual employment		Day programme	
Self employed		Retired	

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

2

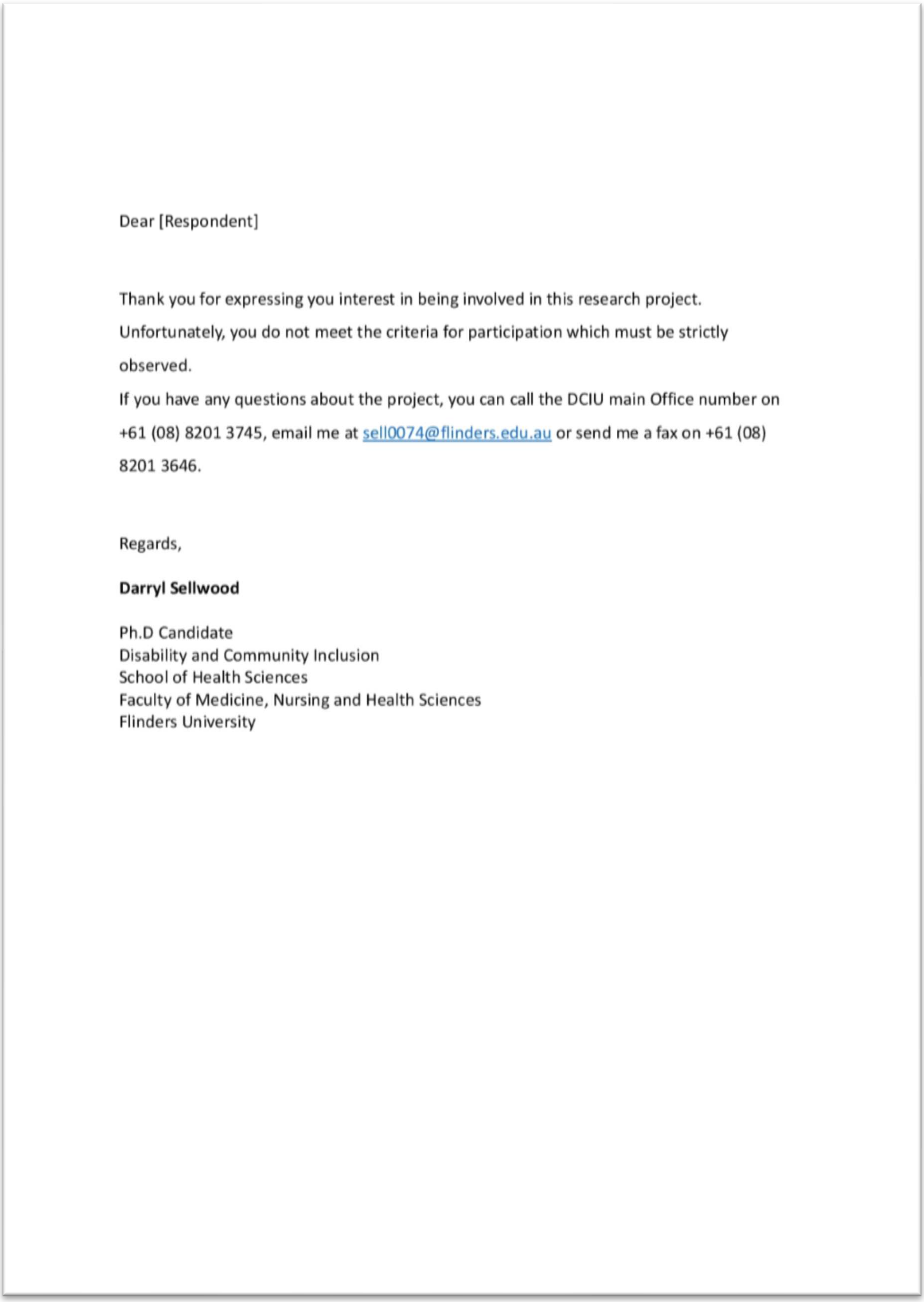


Your Disability							
Primary disability							
Your primary method(s) of communicating							
Natural speech		Gestures or body language		Sign language or finger spelling		AAC device	
Other (please specify)							
Your Communication Strategy							
Your AAC Strategies and devices							
Your access method to your AAC device							

The Project and You	
Do you qualify to take part in this research project?	**Yes/No**
a) Are you over 21years old?	
b) Are you able to understand and communicate in English?	
c) Have you had a physical disability since childhood?	
d) Do you have a disability which affects your use of speech for everyday communication?	
e) Do you use at least one AAC method (communication board or book, speech generating device, iPad)?	
f) Would you be comfortable in discussing your personal relationships?	
Your interview options	**Yes/No**
I would like to be interviewed face to face	
I would like to be interviewed online (Skype)	
I would like someone of my choice to be present as a communication assistant	

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 5. Respondents who do not meet the criteria



Dear [Respondent]

Thank you for expressing you interest in being involved in this research project. Unfortunately, you do not meet the criteria for participation which must be strictly observed.

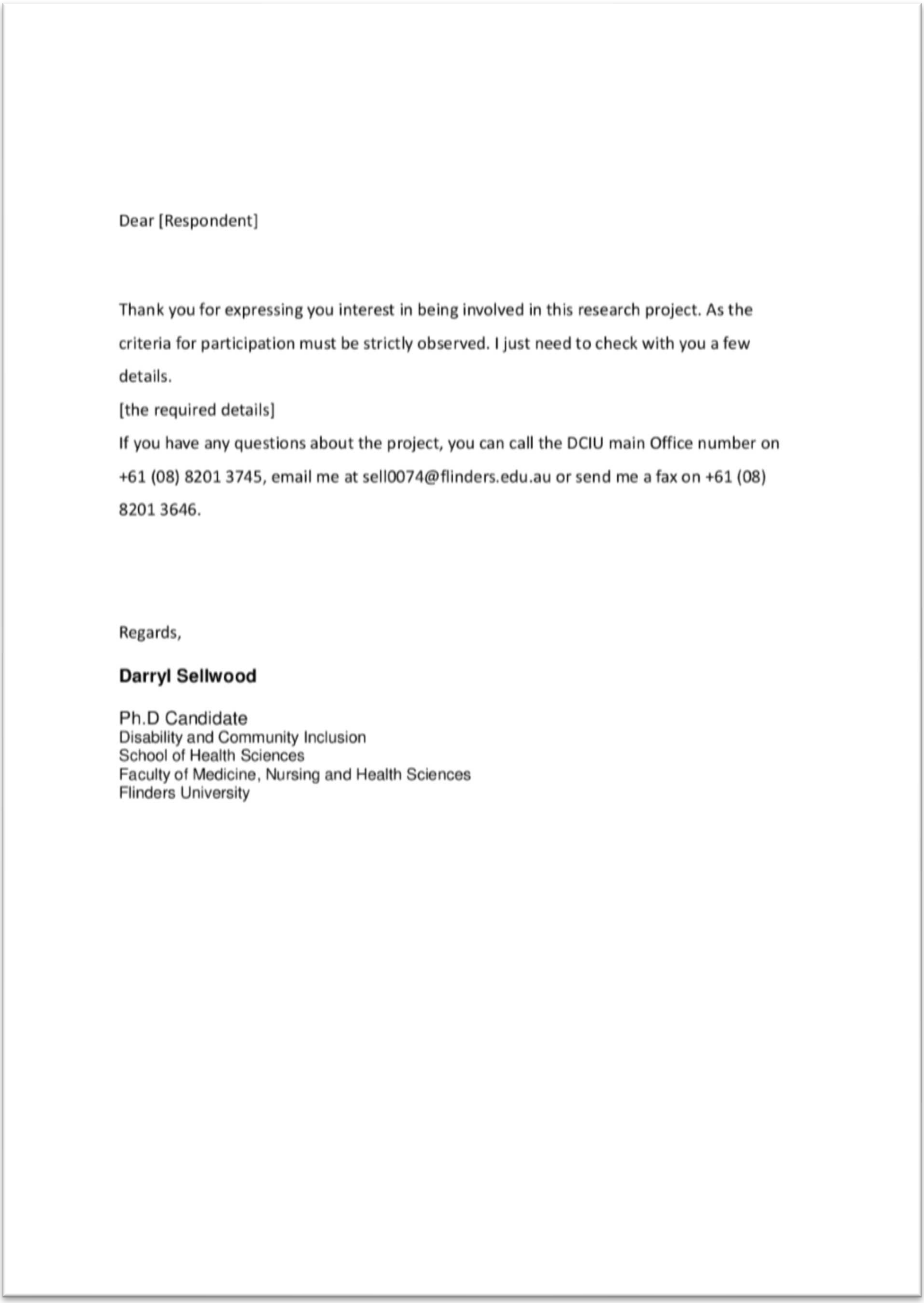
If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email me at sell0074@flinders.edu.au or send me a fax on +61 (08) 8201 3646.

Regards,

Darryl Sellwood

Ph.D Candidate
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University

Appendix 6. Respondents who might not meet the criteria



Dear [Respondent]

Thank you for expressing you interest in being involved in this research project. As the criteria for participation must be strictly observed. I just need to check with you a few details.

[the required details]

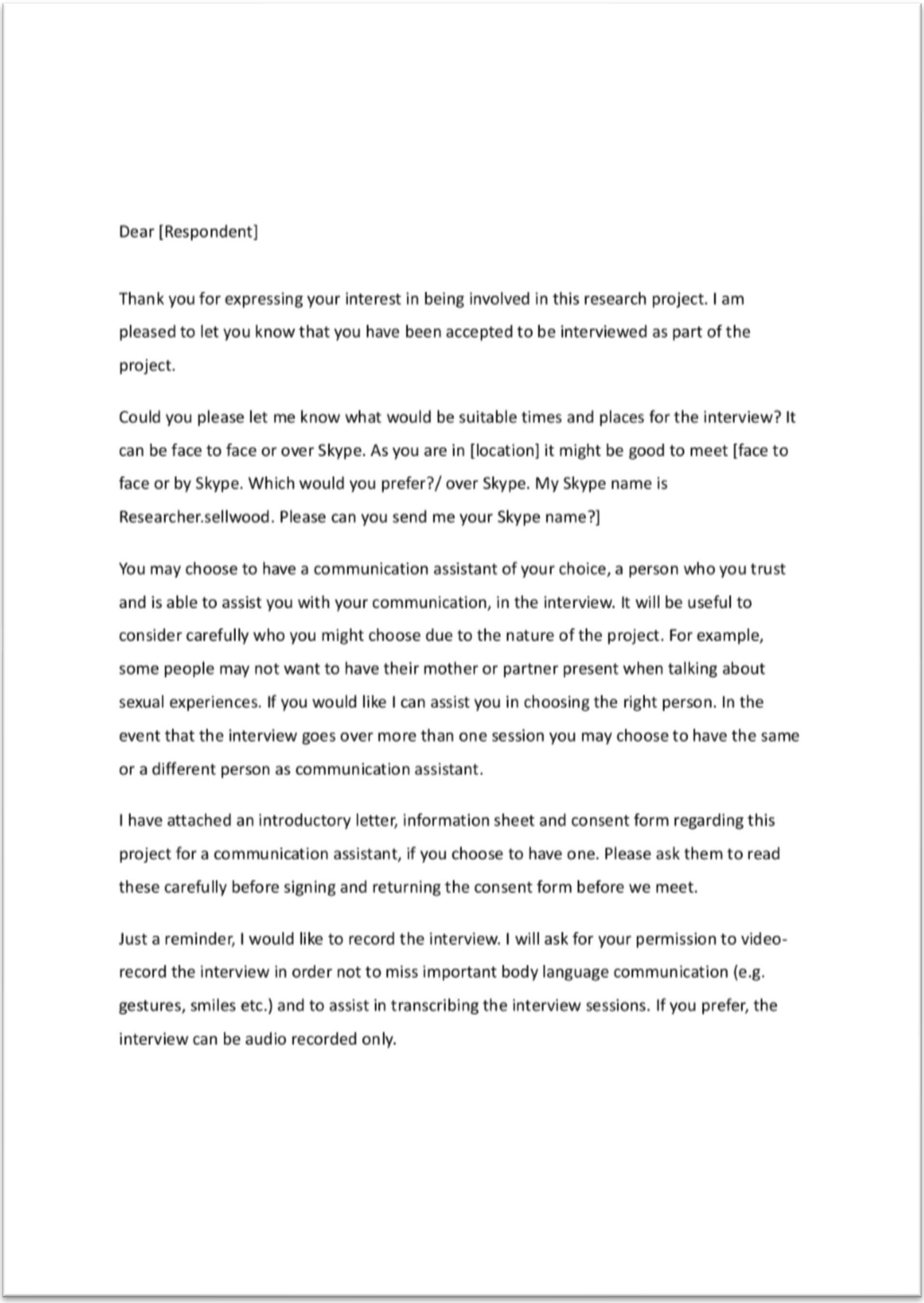
If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email me at sell0074@flinders.edu.au or send me a fax on +61 (08) 8201 3646.

Regards,

Darryl Sellwood

Ph.D Candidate
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University

Appendix 7. Respondents who might meet the criteria



Dear [Respondent]

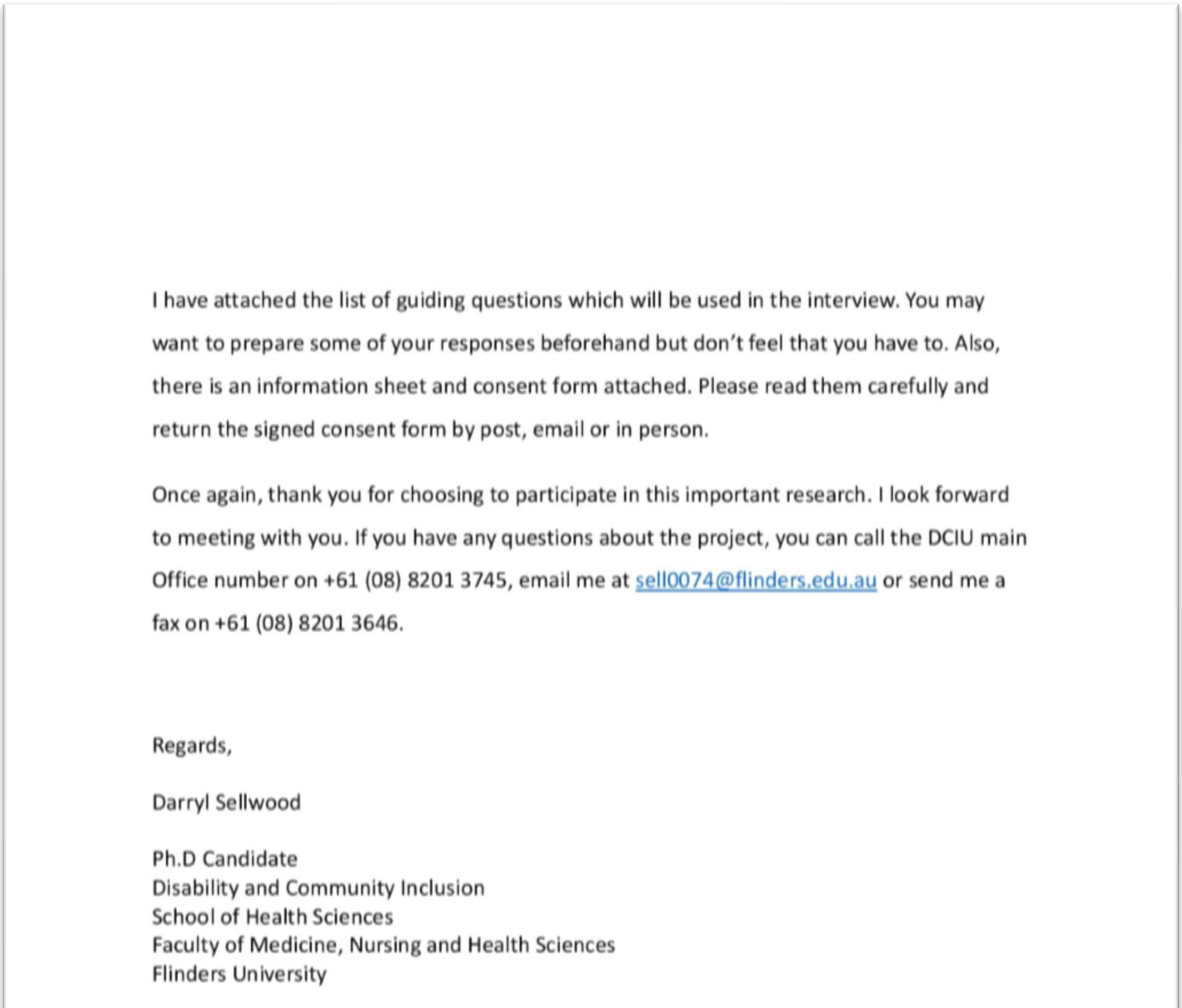
Thank you for expressing your interest in being involved in this research project. I am pleased to let you know that you have been accepted to be interviewed as part of the project.

Could you please let me know what would be suitable times and places for the interview? It can be face to face or over Skype. As you are in [location] it might be good to meet [face to face or by Skype. Which would you prefer?/ over Skype. My Skype name is Researcher.sellwood. Please can you send me your Skype name?]

You may choose to have a communication assistant of your choice, a person who you trust and is able to assist you with your communication, in the interview. It will be useful to consider carefully who you might choose due to the nature of the project. For example, some people may not want to have their mother or partner present when talking about sexual experiences. If you would like I can assist you in choosing the right person. In the event that the interview goes over more than one session you may choose to have the same or a different person as communication assistant.

I have attached an introductory letter, information sheet and consent form regarding this project for a communication assistant, if you choose to have one. Please ask them to read these carefully before signing and returning the consent form before we meet.

Just a reminder, I would like to record the interview. I will ask for your permission to video-record the interview in order not to miss important body language communication (e.g. gestures, smiles etc.) and to assist in transcribing the interview sessions. If you prefer, the interview can be audio recorded only.



I have attached the list of guiding questions which will be used in the interview. You may want to prepare some of your responses beforehand but don't feel that you have to. Also, there is an information sheet and consent form attached. Please read them carefully and return the signed consent form by post, email or in person.

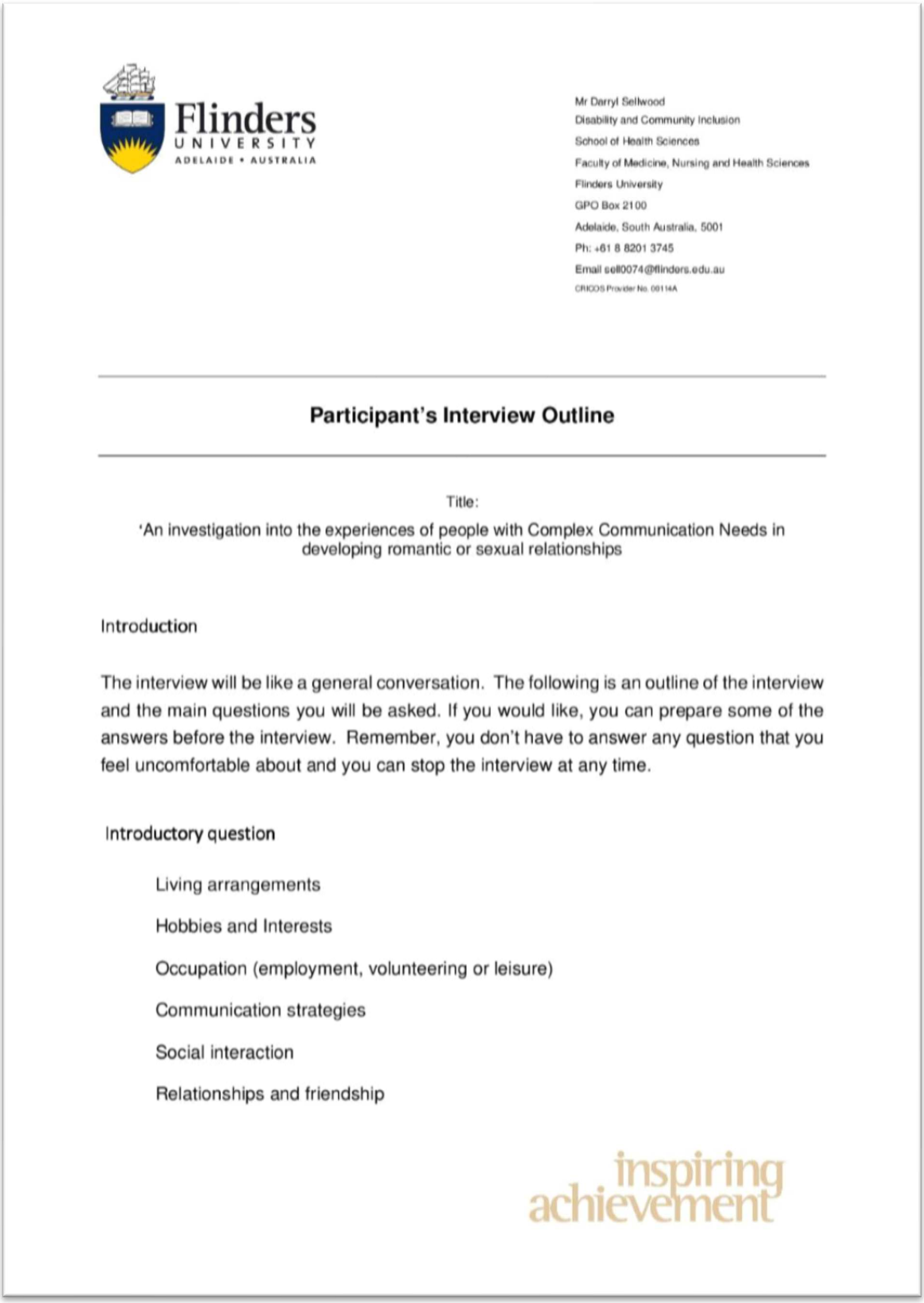
Once again, thank you for choosing to participate in this important research. I look forward to meeting with you. If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email me at sell0074@flinders.edu.au or send me a fax on +61 (08) 8201 3646.

Regards,

Darryl Sellwood

Ph.D Candidate
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University

Appendix 8. Participants Interview Outline



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Mr Darryl Sellwood
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
Adelaide, South Australia, 5001
Ph: +61 8 8201 3745
Email sell0074@flinders.edu.au
CRICOS Provider No. 00114A

Participant's Interview Outline

Title:
'An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships

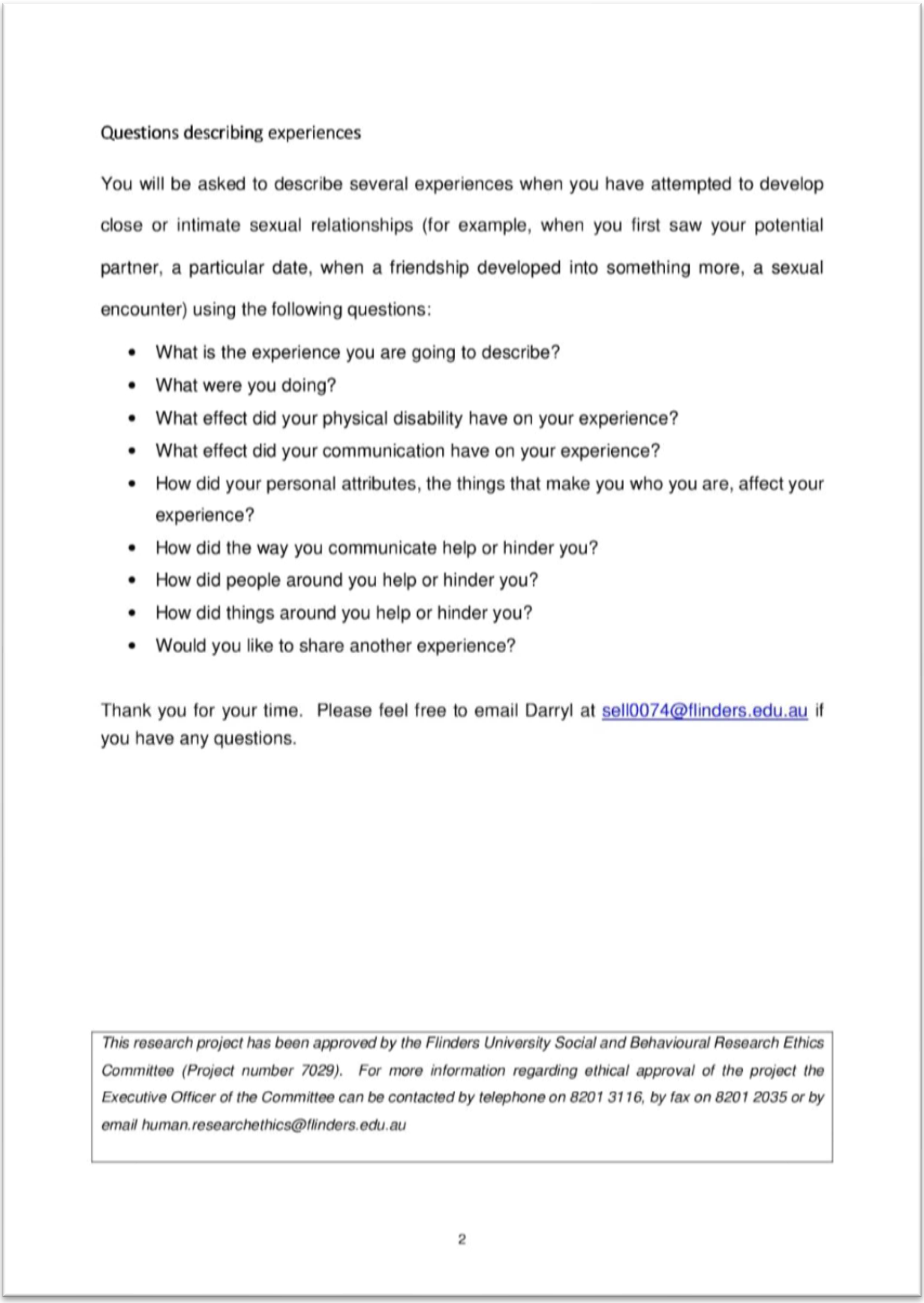
Introduction

The interview will be like a general conversation. The following is an outline of the interview and the main questions you will be asked. If you would like, you can prepare some of the answers before the interview. Remember, you don't have to answer any question that you feel uncomfortable about and you can stop the interview at any time.

Introductory question

Living arrangements
Hobbies and Interests
Occupation (employment, volunteering or leisure)
Communication strategies
Social interaction
Relationships and friendship

inspiring achievement



Questions describing experiences

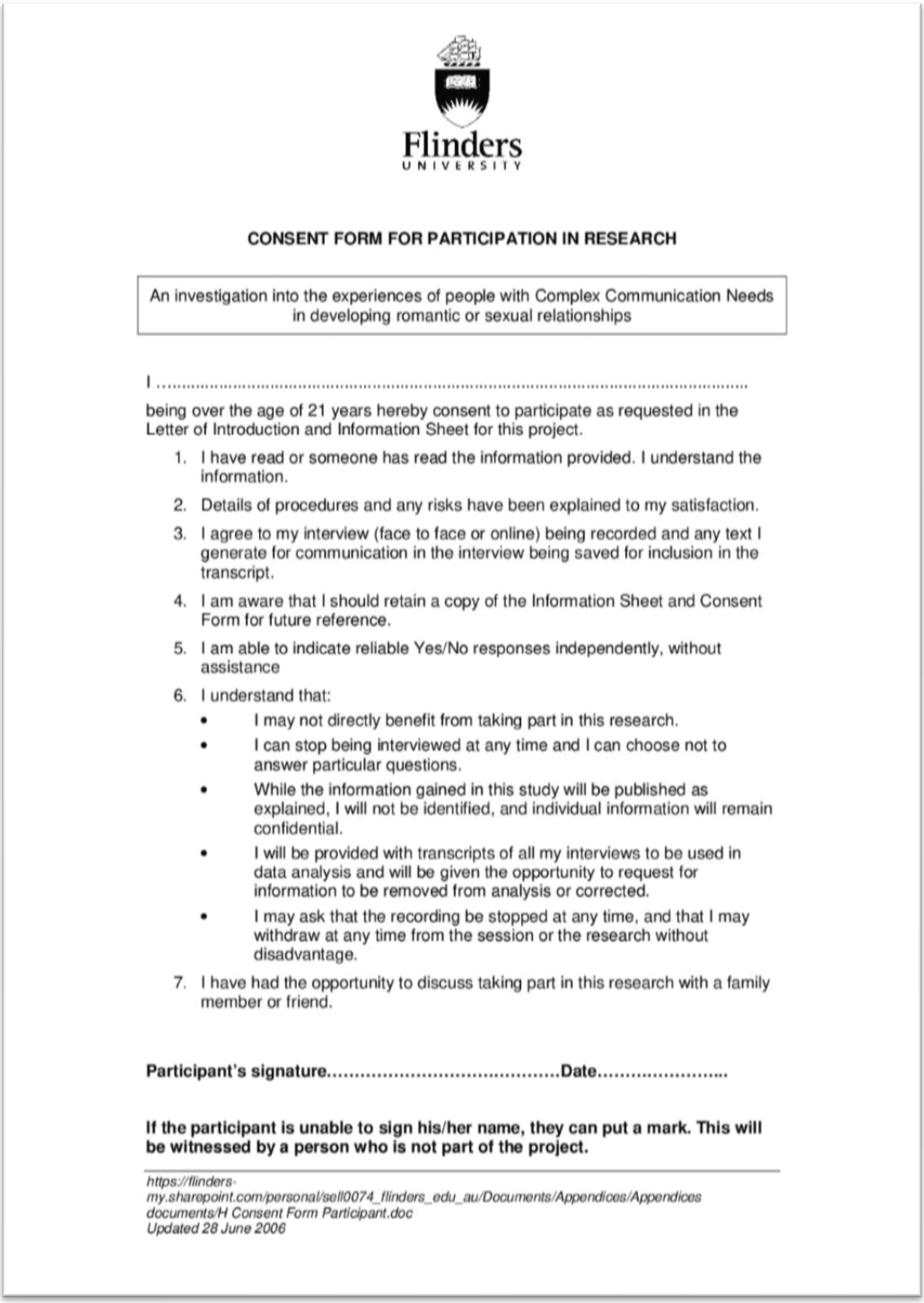
You will be asked to describe several experiences when you have attempted to develop close or intimate sexual relationships (for example, when you first saw your potential partner, a particular date, when a friendship developed into something more, a sexual encounter) using the following questions:

- What is the experience you are going to describe?
- What were you doing?
- What effect did your physical disability have on your experience?
- What effect did your communication have on your experience?
- How did your personal attributes, the things that make you who you are, affect your experience?
- How did the way you communicate help or hinder you?
- How did people around you help or hinder you?
- How did things around you help or hinder you?
- Would you like to share another experience?

Thank you for your time. Please feel free to email Darryl at sell0074@flinders.edu.au if you have any questions.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 9. Participants Consent Form



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CONSENT FORM FOR PARTICIPATION IN RESEARCH

An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships

I ………………………………………………………………………………………………………

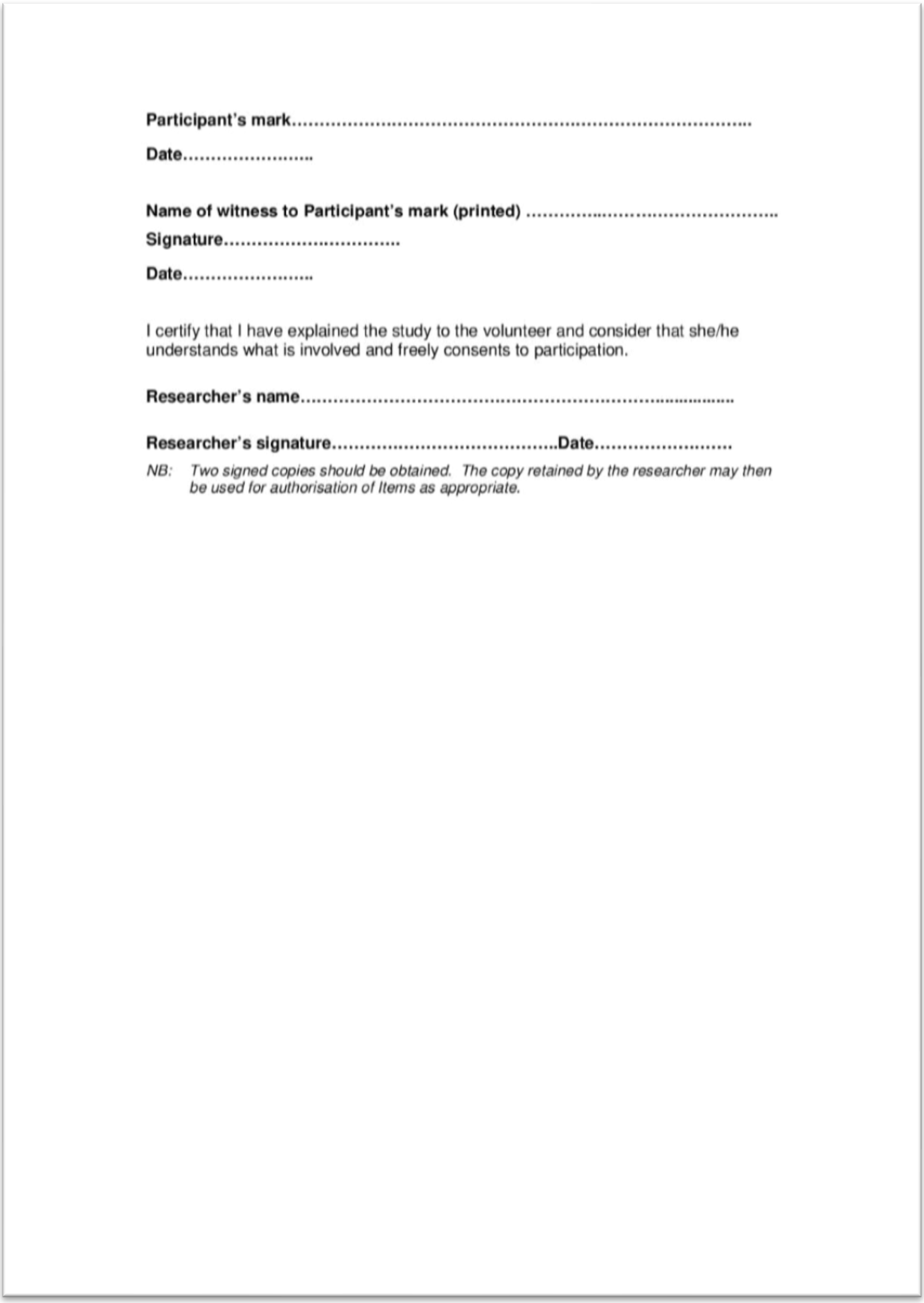
being over the age of 21 years hereby consent to participate as requested in the Letter of Introduction and Information Sheet for this project.

1. I have read or someone has read the information provided. I understand the information.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my interview (face to face or online) being recorded and any text I generate for communication in the interview being saved for inclusion in the transcript.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I am able to indicate reliable Yes/No responses independently, without assistance
6. I understand that:
   - I may not directly benefit from taking part in this research.
   - I can stop being interviewed at any time and I can choose not to answer particular questions.
   - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   - I will be provided with transcripts of all my interviews to be used in data analysis and will be given the opportunity to request for information to be removed from analysis or corrected.
   - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature……………………………………Date…………………..

If the participant is unable to sign his/her name, they can put a mark. This will be witnessed by a person who is not part of the project.

https://flinders-my.sharepoint.com/personal/sell0074_flinders_edu_au/Documents/Appendices/Appendices documents/H Consent Form Participant.doc
Updated 28 June 2006



Participant's mark…………………………………………………………………………..

Date……………………..

Name of witness to Participant's mark (printed) …………..…………………………..

Signature……………….…………..

Date……………………..

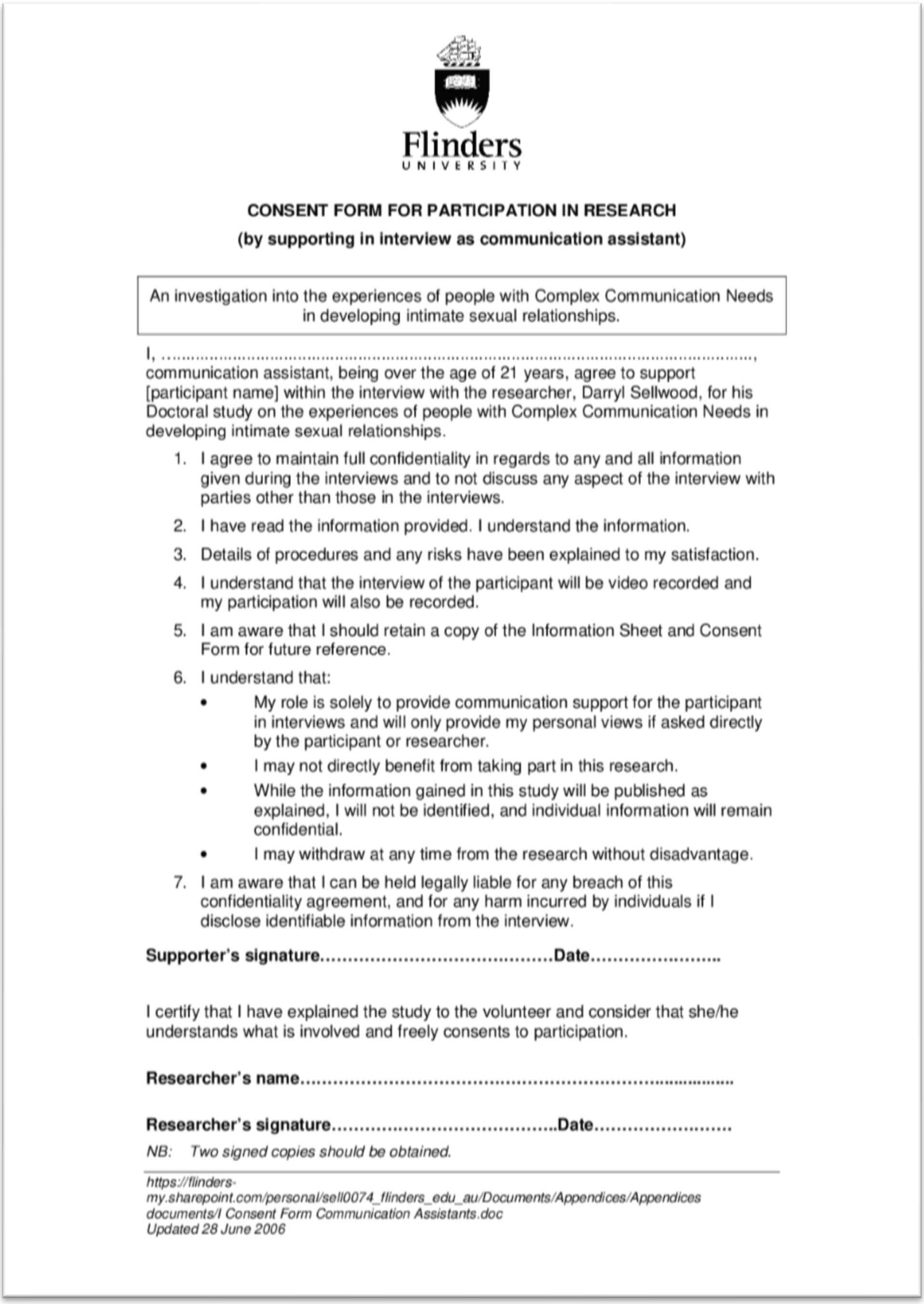
I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………….................

Researcher's signature…………………………………..**Date**…………………….

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items as appropriate.

Appendix 10. Consent Form Communication Assistants



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CONSENT FORM FOR PARTICIPATION IN RESEARCH
(by supporting in interview as communication assistant)

An investigation into the experiences of people with Complex Communication Needs in developing intimate sexual relationships.

I, ……………………………………………………………………………………………………, communication assistant, being over the age of 21 years, agree to support [participant name] within the interview with the researcher, Darryl Sellwood, for his Doctoral study on the experiences of people with Complex Communication Needs in developing intimate sexual relationships.

1. I agree to maintain full confidentiality in regards to any and all information given during the interviews and to not discuss any aspect of the interview with parties other than those in the interviews.
2. I have read the information provided. I understand the information.
3. Details of procedures and any risks have been explained to my satisfaction.
4. I understand that the interview of the participant will be video recorded and my participation will also be recorded.
5. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
6. I understand that:
   - My role is solely to provide communication support for the participant in interviews and will only provide my personal views if asked directly by the participant or researcher.
   - I may not directly benefit from taking part in this research.
   - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   - I may withdraw at any time from the research without disadvantage.
7. I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information from the interview.

Supporter's signature……………………………………Date…………………..

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

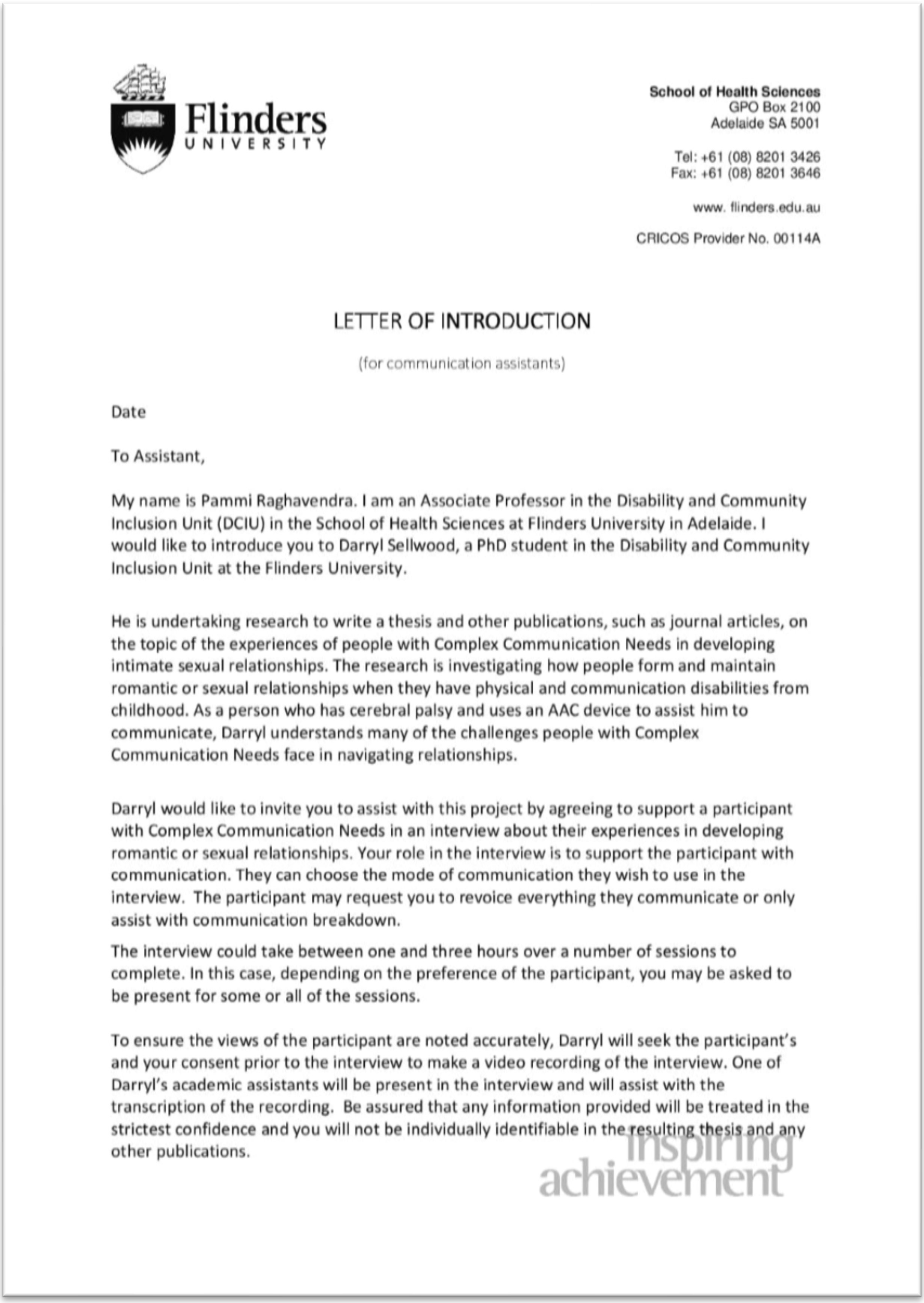
Researcher's name……………………………………………………………………..

Researcher's signature…………………………………..Date……………………..

NB: Two signed copies should be obtained.

https://flinders-my.sharepoint.com/personal/sell0074_flinders_edu_au/Documents/Appendices/Appendices documents/I Consent Form Communication Assistants.doc
Updated 28 June 2006

Appendix 11. Letter of Introduction to Communication Assistants



Flinders
UNIVERSITY

School of Health Sciences
GPO Box 2100
Adelaide SA 5001

Tel: +61 (08) 8201 3426
Fax: +61 (08) 8201 3646

www. flinders.edu.au

CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

(for communication assistants)

Date

To Assistant,

My name is Pammi Raghavendra. I am an Associate Professor in the Disability and Community Inclusion Unit (DCIU) in the School of Health Sciences at Flinders University in Adelaide. I would like to introduce you to Darryl Sellwood, a PhD student in the Disability and Community Inclusion Unit at the Flinders University.

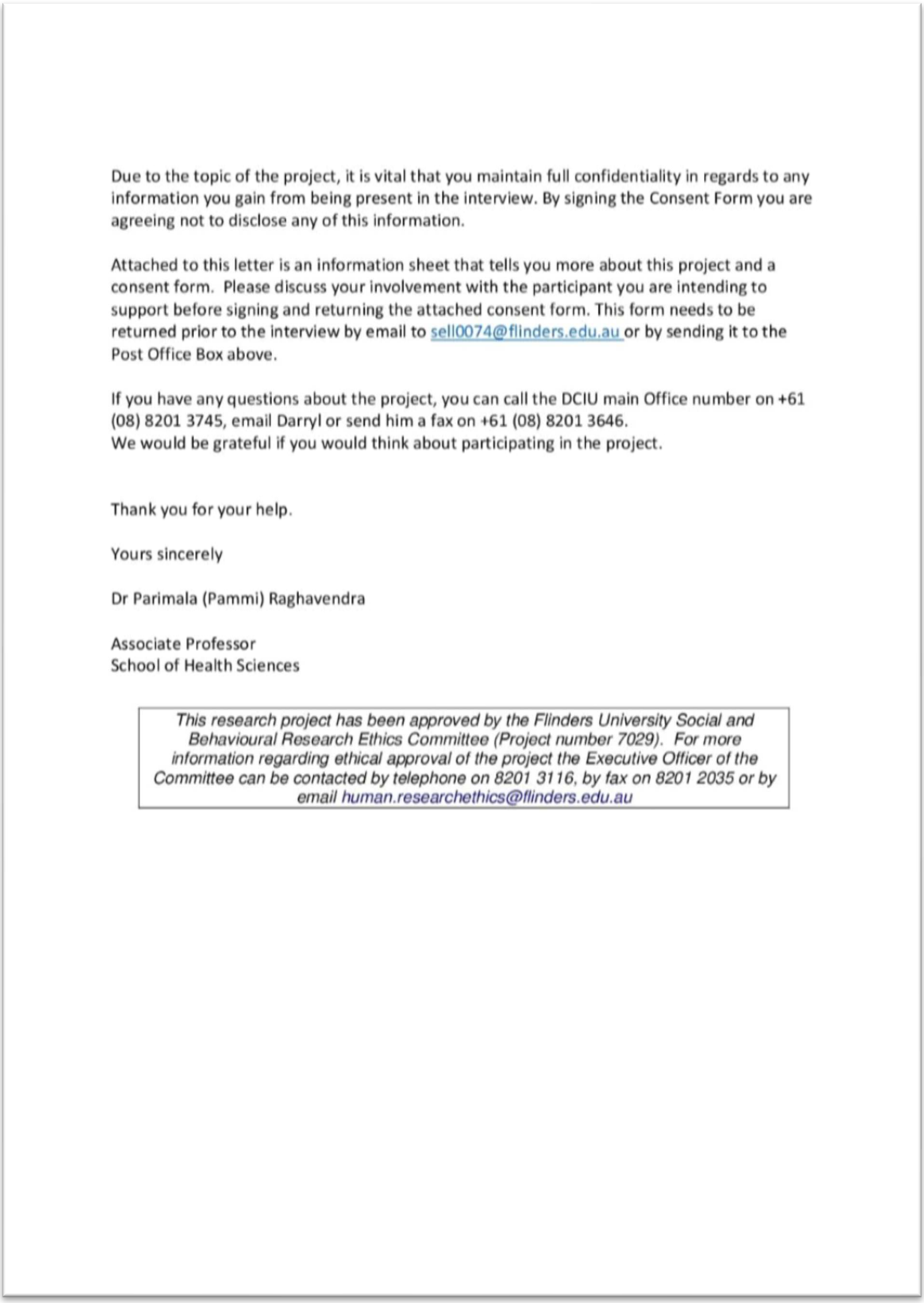
He is undertaking research to write a thesis and other publications, such as journal articles, on the topic of the experiences of people with Complex Communication Needs in developing intimate sexual relationships. The research is investigating how people form and maintain romantic or sexual relationships when they have physical and communication disabilities from childhood. As a person who has cerebral palsy and uses an AAC device to assist him to communicate, Darryl understands many of the challenges people with Complex Communication Needs face in navigating relationships.

Darryl would like to invite you to assist with this project by agreeing to support a participant with Complex Communication Needs in an interview about their experiences in developing romantic or sexual relationships. Your role in the interview is to support the participant with communication. They can choose the mode of communication they wish to use in the interview. The participant may request you to revoice everything they communicate or only assist with communication breakdown.

The interview could take between one and three hours over a number of sessions to complete. In this case, depending on the preference of the participant, you may be asked to be present for some or all of the sessions.

To ensure the views of the participant are noted accurately, Darryl will seek the participant's and your consent prior to the interview to make a video recording of the interview. One of Darryl's academic assistants will be present in the interview and will assist with the transcription of the recording. Be assured that any information provided will be treated in the strictest confidence and you will not be individually identifiable in the resulting thesis and any other publications.

inspiring
achievement



Due to the topic of the project, it is vital that you maintain full confidentiality in regards to any information you gain from being present in the interview. By signing the Consent Form you are agreeing not to disclose any of this information.

Attached to this letter is an information sheet that tells you more about this project and a consent form. Please discuss your involvement with the participant you are intending to support before signing and returning the attached consent form. This form needs to be returned prior to the interview by email to sell0074@flinders.edu.au or by sending it to the Post Office Box above.

If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email Darryl or send him a fax on +61 (08) 8201 3646.
We would be grateful if you would think about participating in the project.

Thank you for your help.

Yours sincerely

Dr Parimala (Pammi) Raghavendra

Associate Professor
School of Health Sciences

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 12. Communication Assistants Information Sheet

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Mr Darryl Sellwood
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
Adelaide, South Australia, 5001
Ph: +61 8 8201 3745
Email sell0074@flinders.edu.au
CRICOS Provider No. 00114A

INFORMATION SHEET
(Communication Assistant)

Title:

'An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships

What is the study about?

This research project is supported by the Disability and Community Inclusion Unit (DCIU) of Flinders University. It investigates the experiences of people with Complex Communication Needs in getting into and keeping romantic or sexual relationships. This research is important because these people are rarely asked about and supported in their love lives. It explores very personal and sensitive issues which are not often discussed. Lovers with physical and communication disabilities receive little support in navigating relationships.

Darryl Sellwood, the researcher, understands many of the challenges people with Complex Communication Needs face as he has cerebral palsy and uses an AAC device to assist him to communicate. He will interview participants to explore their experiences with relationships. The things he discovers could help improve support to these people in order to have loving relationships with boyfriends, girlfriends, husbands and wives. From the information he collects in the interviews, Darryl will write a thesis for his PhD.

Can I participate?

Yes, you can, if you:

- Are at least 21 years old

inspiring
achievement

- communicate in English

What will I be asked to do?

You will be supporting a participant with Complex Communication Needs to be interviewed by Darryl. He will ask the participant to discuss their experiences you have had when you have attempted to start or to maintain a romantic or sexual relationship.

Darryl will ask some open-ended questions and the interview will be like having a conversation. The participant may receive the list of questions before the interview. This will allow time to prepare some of the answers.

What will my role be?

Your role in the interview is to support the participant with communication. They can choose the mode of communication they wish to use in the interview. The participant may request you to revoice everything they communicate or only assist with communication breakdown.

Due to the topic of the project, it is vital that you maintain full confidentiality in regards to any information you gain from being present in the interview. By signing the Consent Form you are agreeing not to disclose any of this information.

Can I give my opinions?

This research deliberately seeks the perspectives of people with Complex Communication Needs. Your role is to support the participant to share their experiences and perspectives. It would be appreciated if you only gave your opinions when they were requested.

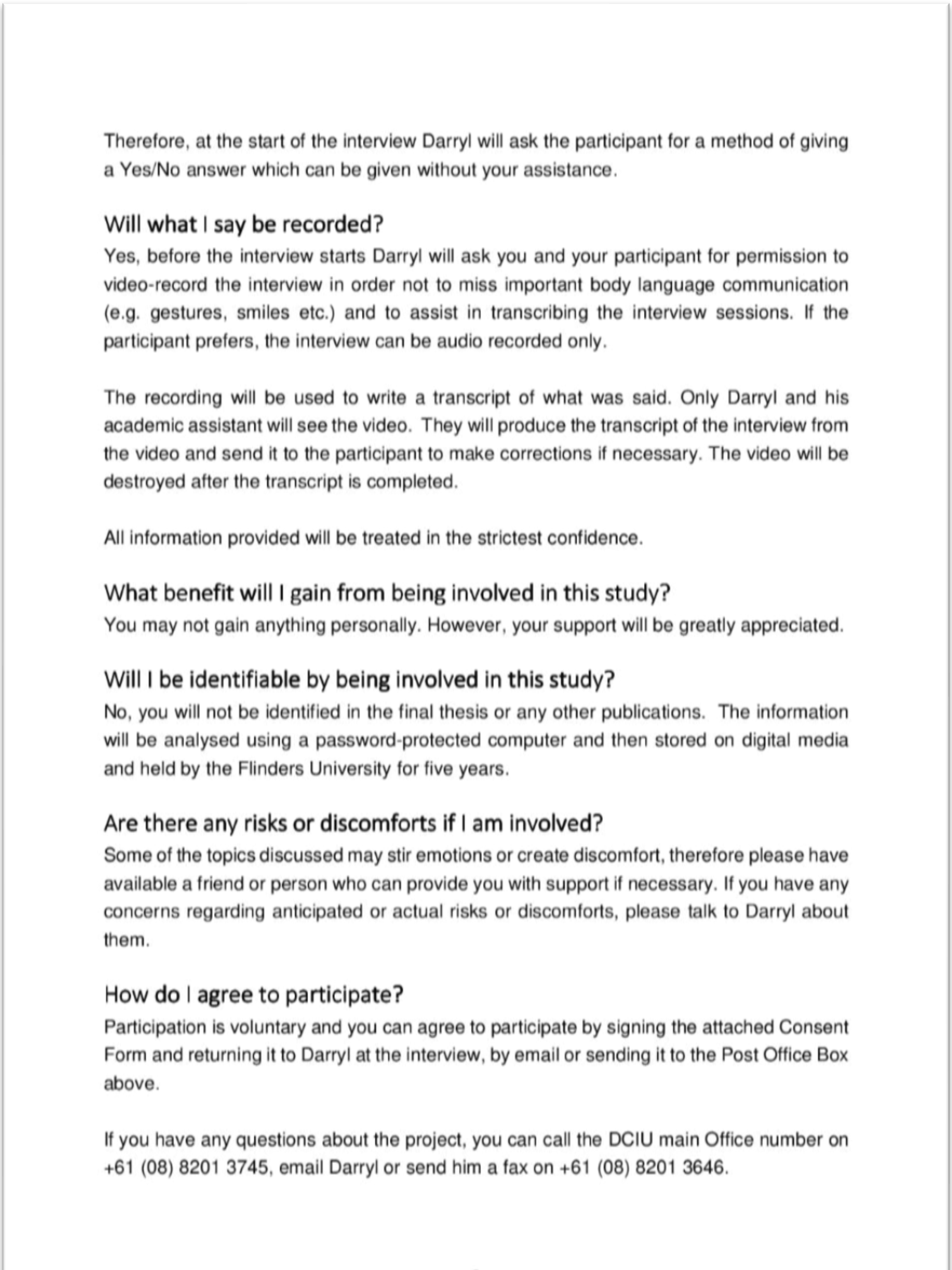
How much time will the interview take?

The interview might take between one and three hours. If the participant chooses to, they may arrange with Darryl to do the interview over a number of sessions. In this case, depending on the preference of the participant, you may be asked to be present for some or all of the sessions.

How will the interview be conducted?

Darryl will organise with the participant a time and place that is suitable to do the interview. It can be in person or by Skype, depending on location and availability. Darryl will conduct the interview using his communication device and his own voice. His academic assistant will also be present to assist him with note taking and communication.

It is important for Darryl to establish the authenticity of the responses of the participant.



Therefore, at the start of the interview Darryl will ask the participant for a method of giving a Yes/No answer which can be given without your assistance.

Will what I say be recorded?

Yes, before the interview starts Darryl will ask you and your participant for permission to video-record the interview in order not to miss important body language communication (e.g. gestures, smiles etc.) and to assist in transcribing the interview sessions. If the participant prefers, the interview can be audio recorded only.

The recording will be used to write a transcript of what was said. Only Darryl and his academic assistant will see the video. They will produce the transcript of the interview from the video and send it to the participant to make corrections if necessary. The video will be destroyed after the transcript is completed.

All information provided will be treated in the strictest confidence.

What benefit will I gain from being involved in this study?

You may not gain anything personally. However, your support will be greatly appreciated.

Will I be identifiable by being involved in this study?

No, you will not be identified in the final thesis or any other publications. The information will be analysed using a password-protected computer and then stored on digital media and held by the Flinders University for five years.

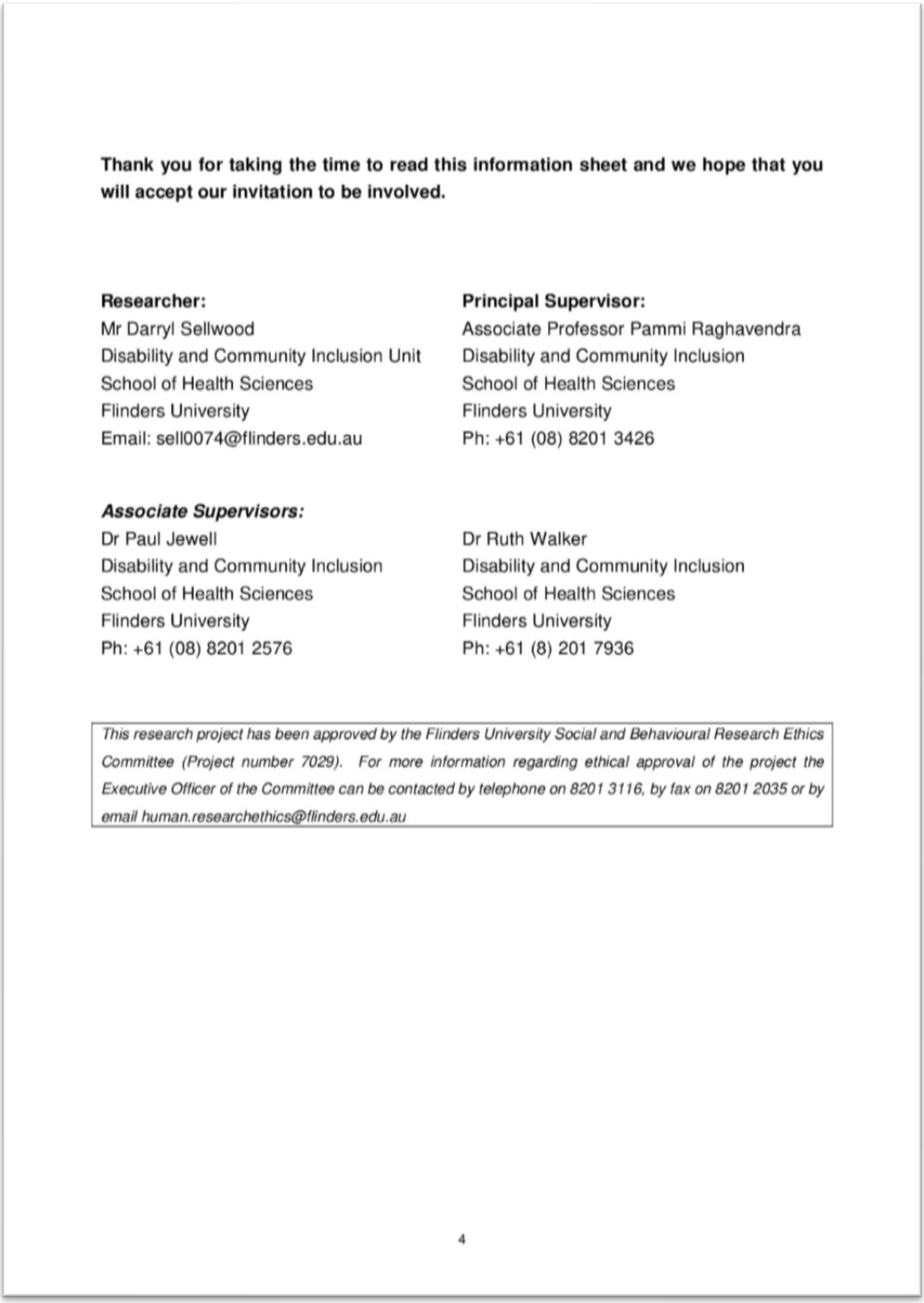
Are there any risks or discomforts if I am involved?

Some of the topics discussed may stir emotions or create discomfort, therefore please have available a friend or person who can provide you with support if necessary. If you have any concerns regarding anticipated or actual risks or discomforts, please talk to Darryl about them.

How do I agree to participate?

Participation is voluntary and you can agree to participate by signing the attached Consent Form and returning it to Darryl at the interview, by email or sending it to the Post Office Box above.

If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email Darryl or send him a fax on +61 (08) 8201 3646.



Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

Researcher:
Mr Darryl Sellwood
Disability and Community Inclusion Unit
School of Health Sciences
Flinders University
Email: sell0074@flinders.edu.au

Principal Supervisor:
Associate Professor Pammi Raghavendra
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (08) 8201 3426

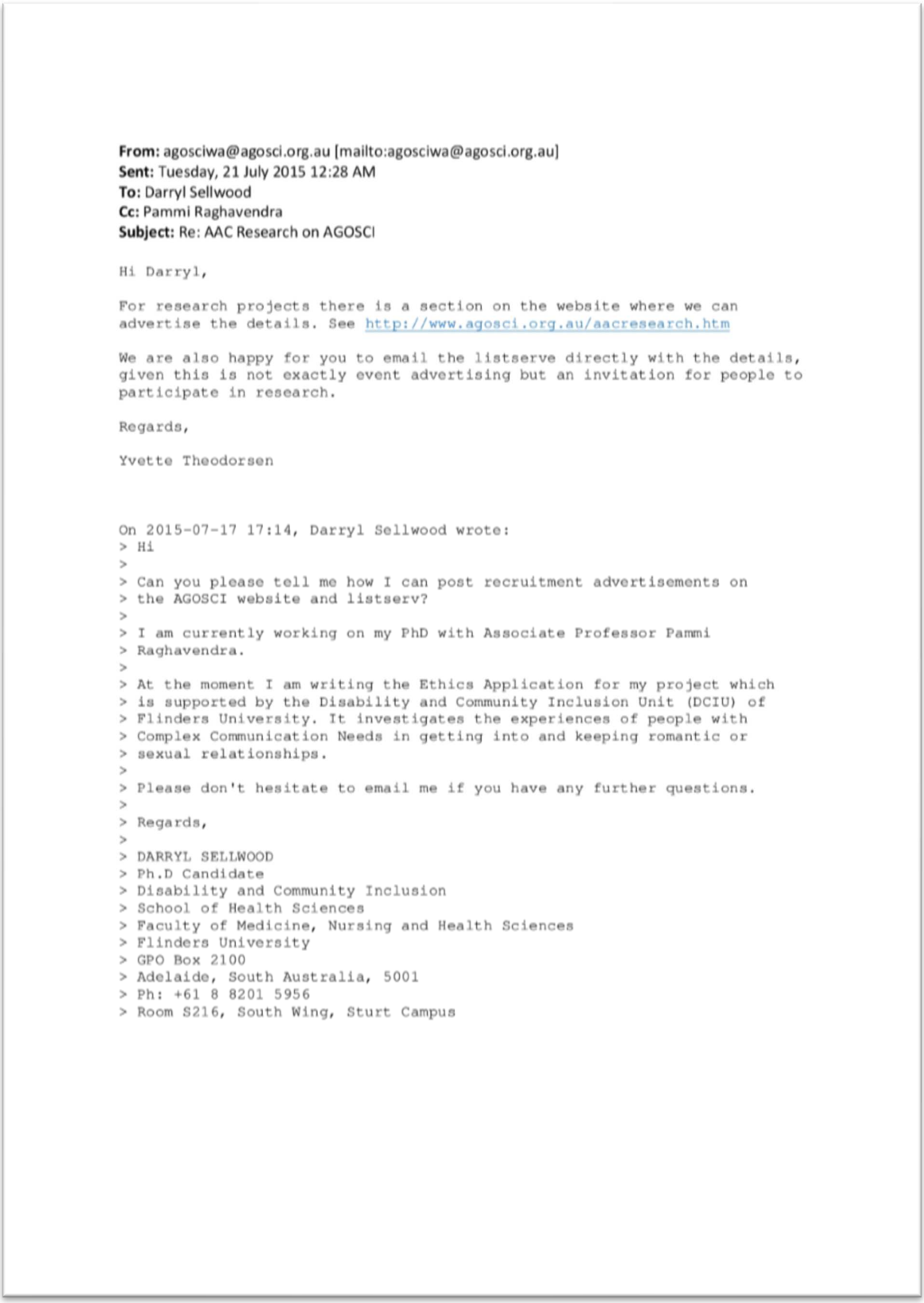
Associate Supervisors:

Dr Paul Jewell
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (08) 8201 2576

Dr Ruth Walker
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (8) 201 7936

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 13. AGOSCI correspondence



From: agosciwa@agosci.org.au [mailto:agosciwa@agosci.org.au]
Sent: Tuesday, 21 July 2015 12:28 AM
To: Darryl Sellwood
Cc: Pammi Raghavendra
Subject: Re: AAC Research on AGOSCI

Hi Darryl,

For research projects there is a section on the website where we can advertise the details. See http://www.agosci.org.au/aacresearch.htm

We are also happy for you to email the listserve directly with the details, given this is not exactly event advertising but an invitation for people to participate in research.

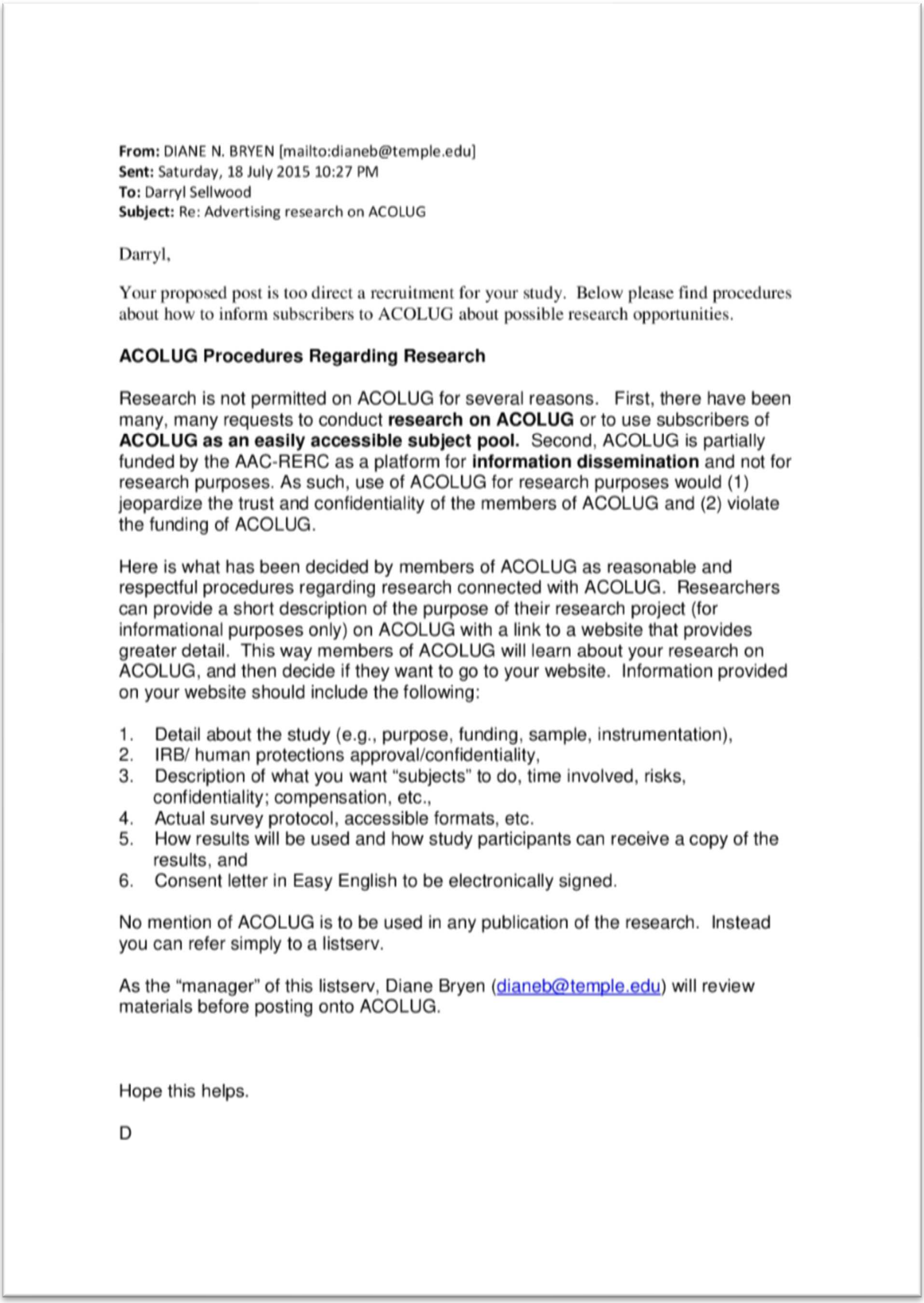
Regards,

Yvette Theodorsen

On 2015-07-17 17:14, Darryl Sellwood wrote:

> Hi
>
> Can you please tell me how I can post recruitment advertisements on the AGOSCI website and listserv?
>
> I am currently working on my PhD with Associate Professor Pammi Raghavendra.
>
> At the moment I am writing the Ethics Application for my project which is supported by the Disability and Community Inclusion Unit (DCIU) of Flinders University. It investigates the experiences of people with Complex Communication Needs in getting into and keeping romantic or sexual relationships.
>
> Please don't hesitate to email me if you have any further questions.
>
> Regards,
>
> DARRYL SELLWOOD
> Ph.D Candidate
> Disability and Community Inclusion
> School of Health Sciences
> Faculty of Medicine, Nursing and Health Sciences
> Flinders University
> GPO Box 2100
> Adelaide, South Australia, 5001
> Ph: +61 8 8201 5956
> Room S216, South Wing, Sturt Campus

Appendix 14. ACOLUG Correspondence



From: DIANE N. BRYEN [mailto:dianeb@temple.edu]
Sent: Saturday, 18 July 2015 10:27 PM
To: Darryl Sellwood
Subject: Re: Advertising research on ACOLUG

Darryl,

Your proposed post is too direct a recruitment for your study. Below please find procedures about how to inform subscribers to ACOLUG about possible research opportunities.

ACOLUG Procedures Regarding Research

Research is not permitted on ACOLUG for several reasons. First, there have been many, many requests to conduct **research on ACOLUG** or to use subscribers of **ACOLUG as an easily accessible subject pool.** Second, ACOLUG is partially funded by the AAC-RERC as a platform for **information dissemination** and not for research purposes. As such, use of ACOLUG for research purposes would (1) jeopardize the trust and confidentiality of the members of ACOLUG and (2) violate the funding of ACOLUG.

Here is what has been decided by members of ACOLUG as reasonable and respectful procedures regarding research connected with ACOLUG. Researchers can provide a short description of the purpose of their research project (for informational purposes only) on ACOLUG with a link to a website that provides greater detail. This way members of ACOLUG will learn about your research on ACOLUG, and then decide if they want to go to your website. Information provided on your website should include the following:

1. Detail about the study (e.g., purpose, funding, sample, instrumentation),
2. IRB/ human protections approval/confidentiality,
3. Description of what you want “subjects” to do, time involved, risks, confidentiality; compensation, etc.,
4. Actual survey protocol, accessible formats, etc.
5. How results will be used and how study participants can receive a copy of the results, and
6. Consent letter in Easy English to be electronically signed.

No mention of ACOLUG is to be used in any publication of the research. Instead you can refer simply to a listserv.

As the “manager” of this listserv, Diane Bryen (dianeb@temple.edu) will review materials before posting onto ACOLUG.

Hope this helps.

D

On Wed, Jul 15, 2015 at 9:32 PM, Darryl Sellwood <sell0074@uni.flinders.edu.au> wrote:

Hi Diane

I forgot to ask you in my last email about advertising on ACOLUG. I wasn't sure what you were meaning. Is it possible to advertise research by putting up information about it and inviting people to click on a link for more information or is there a ban on recruitment information?

This is a proposed email recruitment advertisement:

> Have you had:
>
> - A desire to enter into a romantic or sexual relationship?
> - A friendship that you hoped would develop into more than a friendship?
> - A girlfriend and/or boyfriend?
> - Something stopping you from developing a romantic or sexual relationship?
>
> Some people have been creatively successful in their loving relationships, while for others just find getting past "let's just be good friends" is a faraway dream. Having a physical disability and difficulty in using speech for everyday communication can create further challenges. I know this from my own experience as a person who uses an electric wheelchair for mobility and an AAC device to support my communication due to cerebral palsy. I imagine others share similar experiences. So, as a part of my PhD research at the Flinders University, I am looking for people with physical and communication disabilities to interview, face to face or over Skype, to share their experiences of romantic or sexual relationships. Some participants may choose to have a communication assistant of their choice in interviews.
>
> I would like to invite you to participate in interviews for this research project to share some of your experiences, pleasurable and not so pleasurable moments. Your name or identity will not be revealed and the confidentiality of all information is respected and maintained.
>
> You can read more information about the project and register your interest here:
>
> [tidyurl here to the website]
>
> If you would like to know more, please feel free to email Darryl at sell0074@flinders.edu.au

Thanks

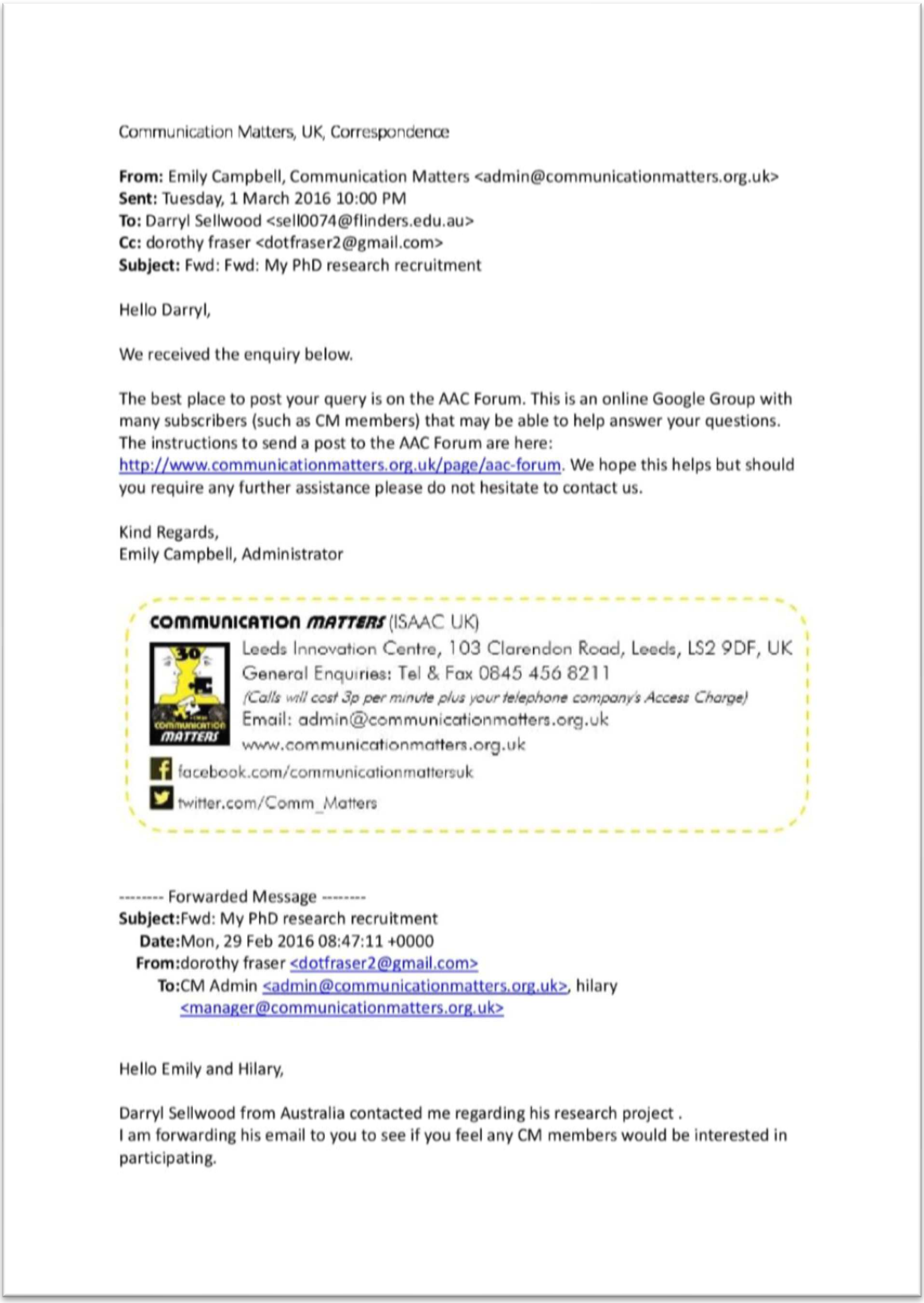
Regards,

Darryl Sellwood
Ph.D Candidate
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University

GPO Box 2100
Adelaide, South Australia, 5001
Ph: +61 8 8201 5956

Room S216, South Wing, Sturt Campus

Appendix 15. Communication Matters Correspondence



Communication Matters, UK, Correspondence

From: Emily Campbell, Communication Matters <admin@communicationmatters.org.uk>
Sent: Tuesday, 1 March 2016 10:00 PM
To: Darryl Sellwood <sell0074@flinders.edu.au>
Cc: dorothy fraser <dotfraser2@gmail.com>
Subject: Fwd: Fwd: My PhD research recruitment

Hello Darryl,

We received the enquiry below.

The best place to post your query is on the AAC Forum. This is an online Google Group with many subscribers (such as CM members) that may be able to help answer your questions. The instructions to send a post to the AAC Forum are here: http://www.communicationmatters.org.uk/page/aac-forum. We hope this helps but should you require any further assistance please do not hesitate to contact us.

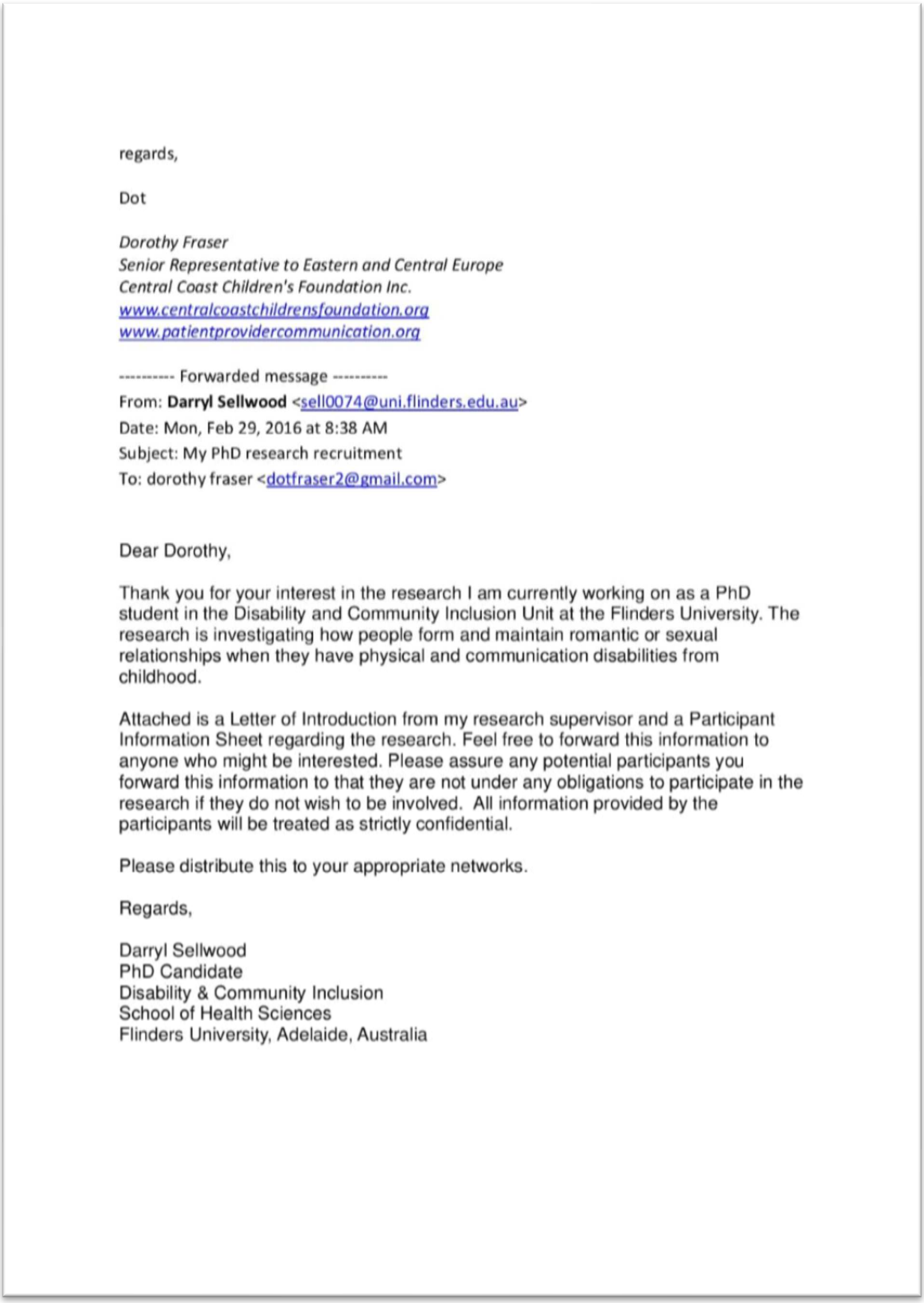
Kind Regards,
Emily Campbell, Administrator

COMMUNICATION MATTERS (ISAAC UK)
Leeds Innovation Centre, 103 Clarendon Road, Leeds, LS2 9DF, UK
General Enquiries: Tel & Fax 0845 456 8211
(Calls will cost 3p per minute plus your telephone company's Access Charge)
Email: admin@communicationmatters.org.uk
www.communicationmatters.org.uk
facebook.com/communicationmattersuk
twitter.com/Comm_Matters

-------- Forwarded Message --------
Subject: Fwd: My PhD research recruitment
Date: Mon, 29 Feb 2016 08:47:11 +0000
From:dorothy fraser <dotfraser2@gmail.com>
To:CM Admin <admin@communicationmatters.org.uk>, hilary <manager@communicationmatters.org.uk>

Hello Emily and Hilary,

Darryl Sellwood from Australia contacted me regarding his research project .
I am forwarding his email to you to see if you feel any CM members would be interested in participating.



regards,

Dot

Dorothy Fraser
Senior Representative to Eastern and Central Europe
Central Coast Children's Foundation Inc.
www.centralcoastchildrensfoundation.org
www.patientprovidercommunication.org

---------- Forwarded message ----------
From: **Darryl Sellwood** <sell0074@uni.flinders.edu.au>
Date: Mon, Feb 29, 2016 at 8:38 AM
Subject: My PhD research recruitment
To: dorothy fraser <dotfraser2@gmail.com>

Dear Dorothy,

Thank you for your interest in the research I am currently working on as a PhD student in the Disability and Community Inclusion Unit at the Flinders University. The research is investigating how people form and maintain romantic or sexual relationships when they have physical and communication disabilities from childhood.

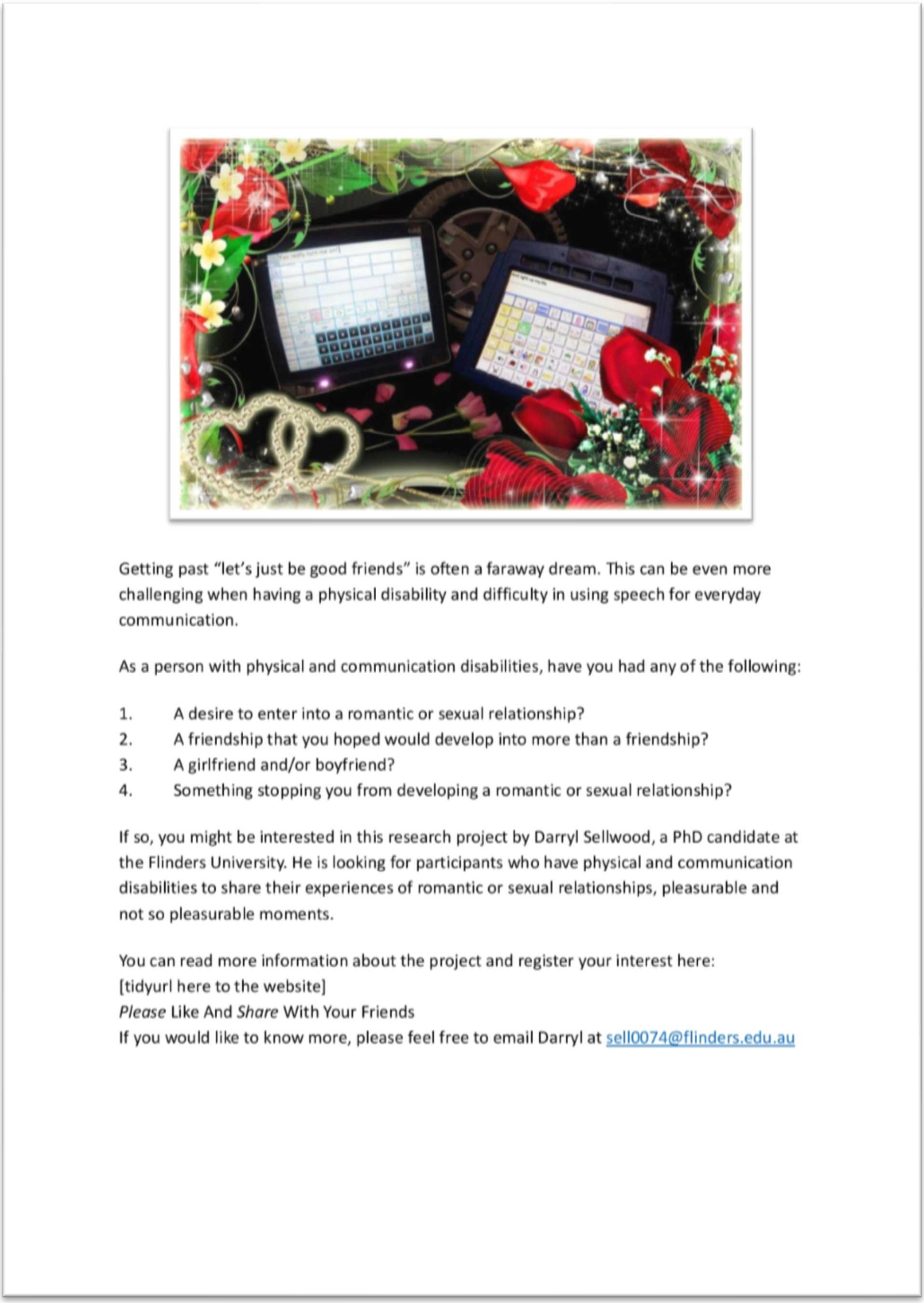
Attached is a Letter of Introduction from my research supervisor and a Participant Information Sheet regarding the research. Feel free to forward this information to anyone who might be interested. Please assure any potential participants you forward this information to that they are not under any obligations to participate in the research if they do not wish to be involved. All information provided by the participants will be treated as strictly confidential.

Please distribute this to your appropriate networks.

Regards,

Darryl Sellwood
PhD Candidate
Disability & Community Inclusion
School of Health Sciences
Flinders University, Adelaide, Australia

Appendix 16. Facebook



Getting past "let's just be good friends" is often a faraway dream. This can be even more challenging when having a physical disability and difficulty in using speech for everyday communication.

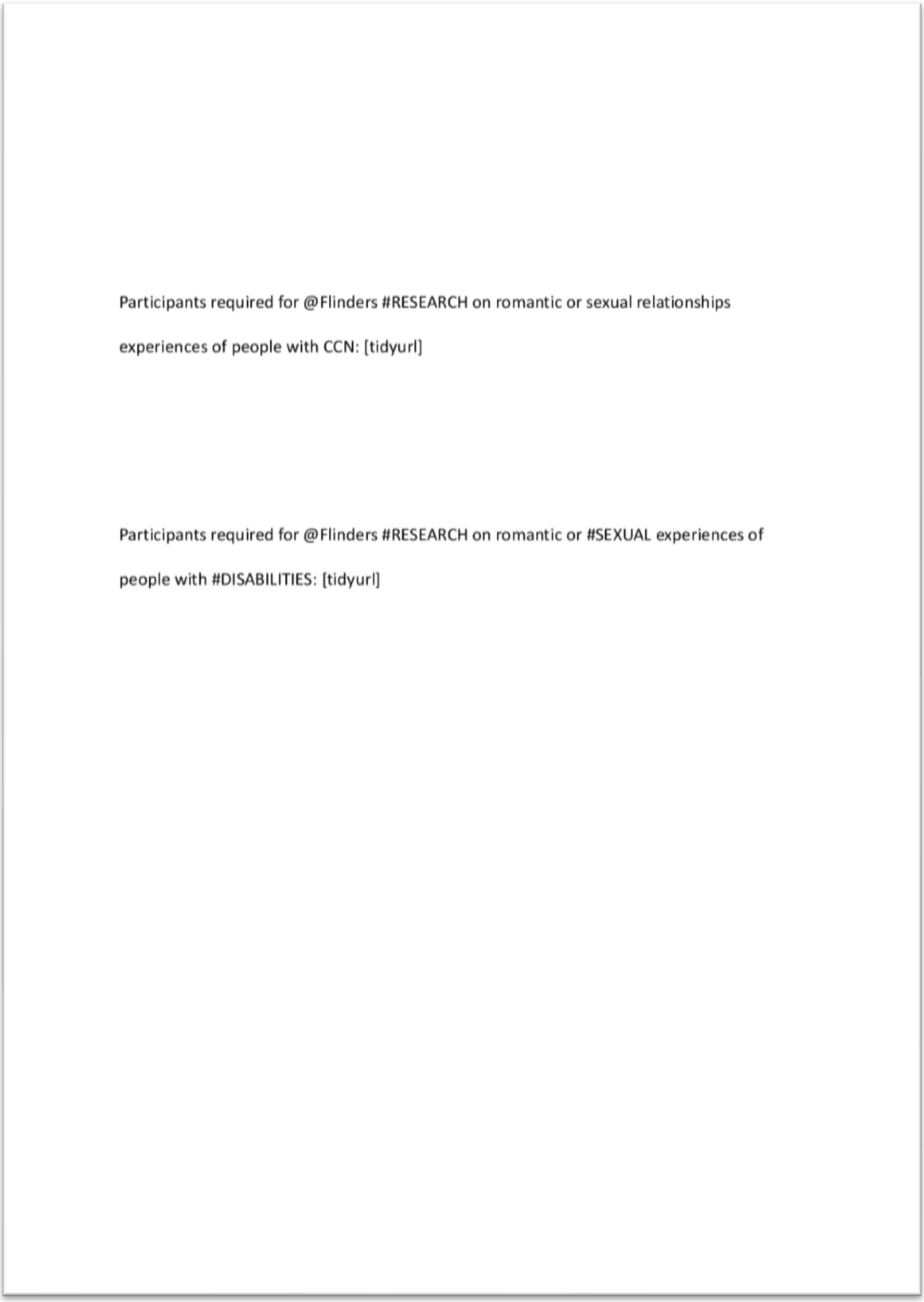
As a person with physical and communication disabilities, have you had any of the following:

1. A desire to enter into a romantic or sexual relationship?
2. A friendship that you hoped would develop into more than a friendship?
3. A girlfriend and/or boyfriend?
4. Something stopping you from developing a romantic or sexual relationship?

If so, you might be interested in this research project by Darryl Sellwood, a PhD candidate at the Flinders University. He is looking for participants who have physical and communication disabilities to share their experiences of romantic or sexual relationships, pleasurable and not so pleasurable moments.

You can read more information about the project and register your interest here:
[tidyurl here to the website]
Please Like And *Share* With Your Friends
If you would like to know more, please feel free to email Darryl at sell0074@flinders.edu.au

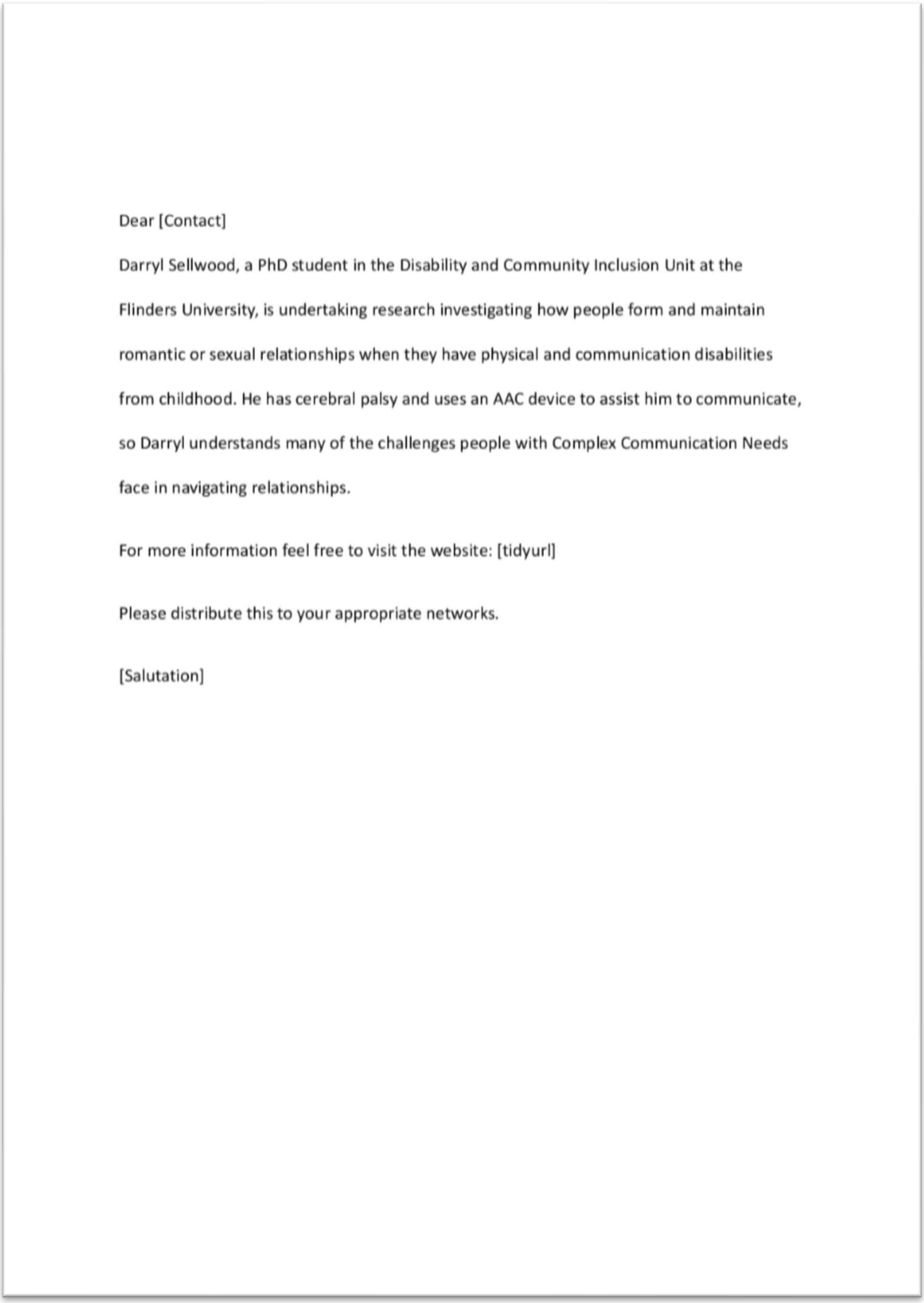
Appendix 17. Twitter



Participants required for @Flinders #RESEARCH on romantic or sexual relationships experiences of people with CCN: [tidyurl]

Participants required for @Flinders #RESEARCH on romantic or #SEXUAL experiences of people with #DISABILITIES: [tidyurl]

Appendix 18. Snowball Email



Dear [Contact]

Darryl Sellwood, a PhD student in the Disability and Community Inclusion Unit at the Flinders University, is undertaking research investigating how people form and maintain romantic or sexual relationships when they have physical and communication disabilities from childhood. He has cerebral palsy and uses an AAC device to assist him to communicate, so Darryl understands many of the challenges people with Complex Communication Needs face in navigating relationships.

For more information feel free to visit the website: [tidyurl]

Please distribute this to your appropriate networks.

[Salutation]

Appendix 19. Direct email contact

Subject: My research project

Dear [Contact]

As you might know I am currently looking for people to interview as a part of my PhD research. The project is investigating the experiences of people with Complex Communication Needs in developing romantic or sexual relationships. If you are in agreeance I would like to invite you to participate. I believe you would have valuable experience and insight in this area that might be of benefit to others.

You have probably seen the recruitment material for my project posted on the Internet and in emails. Usually, researchers are discouraged from directly asking people they know to participate in their research projects, especially on a topic such as mine. This is because it might be seen to be coercion or putting people on the spot. To overcome this issue, I have received permission from the university to invite people directly.

I have attached some information explaining the project in more detail. If you are interested, I would like to have the opportunity to interview you. Please be reassured that I will not be offended if you choose not to participate. I understand you might not feel comfortable talking to me about these kinds of issues. However, if you are interested please contact me directly or register your interest on the website at http://tinyurl.com/RSRccn

And if you can think anyone else who might be interested in participating in this research please encourage them to contact me or visit the research website.

Thank you for taking the time to consider this.

Regards

[Salutation]

Appendix 20. Direct approach scripts

Script for research introduction and invitation

The following is the proposed script for me to use when talking to potential participants:

> "I am doing a PhD at Flinders University in Australia. I think you might find it interesting. Could I spend a few minutes talking about my research?
> My research is about the experiences people with CCN have in developing romantic or sexual relationships. I am interviewing people about their personal experiences in the hope that what they say will help others like themselves to develop satisfying relationships and possibly influence services to improve their support for people with CCN. Can I give you a pamphlet with some more information? It has a link to a site where you can get more information and register your interest if you would like to participate.
> Feel free to discuss this with me or [my supervisor/assistant]. We will be happy to answer any questions you may have."

The following is the proposed script for my supervisor and assistant to use when talking to potential participants:

> "You may have seen Darryl around [at the conference]. He is doing a PhD at Flinders University in Australia and I am his Supervisor/Assistant for his research. I think you might find it interesting. Could I spend a few minutes talking about the research?
> Darryl's research is about the experiences people with CCN have in developing romantic or sexual relationships. He is interviewing people about their personal experiences in the hope that what they say will help others like themselves to develop satisfying relationships and possibly influence services to improve their support for people with CCN. Can I give you a pamphlet with some more information? It has a link to a site where you can get more information and register your interest if you would like to participate.
> I will be happy to discuss this with you and answer any questions you may have."

Appendix 21. Recruitment pamphlet

The Researcher

Darryl Sellwood, the researcher, understands many of the challenges people with Complex Communication Needs (CCN) face as he has cerebral palsy and uses an Augmentative and Alternative Communication (AAC) device to assist him to communicate. He will interview participants to explore their experiences with romantic or sexual relationships. The things he discovers could help improve support to people with CCN in order to have loving relationships with boyfriends, girlfriends, husbands and wives. From the information he collects in the interviews, Darryl will write a thesis for his PhD.

Can I participate?

Yes, you can, if you:

- are at least 21 years old
- can communicate in English
- have had a physical disability since childhood
- have complex communication needs
- use at least one AAC method (eg communication board or book, speech generating device, iPad).
- can provide reliable Yes/No responses independently, without assistance
- understand what you will be asked to do in this project and can indicate that you would like to participate.

What will I be asked to do?

You will be interviewed by Darryl. You will be asked about experiences you have had when you have attempted to start or to maintain a romantic or sexual relationship.

Darryl will ask some open-ended questions and the interview will be like having a conversation. Darryl can send you the list of questions before the interview. This will give you time to prepare some of your answers.

How much time will it take?

The interview might take between one and two hours. If you need to you can arrange with Darryl to do the interview over a number of sessions. An optional follow up interview of up to one hour will be available if you would like to provide any clarifications or additional information.

How will it work?

Darryl will organise with you a time and place that is suitable for you to do the interview. It can be in person or by Skype, depending on your location and availability. Darryl will interview you using his communication device and his own voice. His academic assistant will also be present to assist Darryl with note taking and communication.

You may choose to have a communication assistant of your choice in the interview.

Will I be recorded?

With your permission the interview will be video-recorded. This will be used to write a transcript of the interview. Only Darryl, his three supervisors and his academic assistants will view the interview. All data are securely stored on a password protected computer. All information provided will be treated in the strictest confidence.

Will I be identifiable?

No, you will not be identified in the final thesis or any other publications.

Are there any risks?

Some of the topics discussed may stir emotions or create discomfort. Please have available someone who can provide you with support if necessary.

How do I participate?

If you are interested in participating in this research, please visit http://tinyurl.com/RSRccn. Darryl will let you know that he has received your Expression of Interest by email or post. If you meet the participation criteria for this project, he will arrange an interview with you.

You should retain a copy of the Information Sheet and Consent Form for future reference.

If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email Darryl or send him a fax on +61 (08) 8201 3646.

Researcher

Mr Darryl Sellwood
Disability and Community Inclusion Unit
School of Health Sciences
Flinders University
Email: sell0074@flinders.edu.au

Principal Supervisor

Associate Professor Pammi Raghavendra
Disability and Community Inclusion Unit
School of Health Sciences
Flinders University
Ph: +61 (08) 8201 3426

Associate Supervisors

Dr Paul Jewell
Disability and Community Inclusion Unit
School of Health Sciences
Flinders University
Ph: +61 (08) 8201 2576

Dr Ruth Walker
Disability and Community Inclusion Unit
School of Health Sciences
Flinders University
Ph: +61 (8) 201 7936

> *This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by emailing human.researchethics@flinders.edu.au*

DBR Desktop Publishing
dbroberts@adelaide.on.net

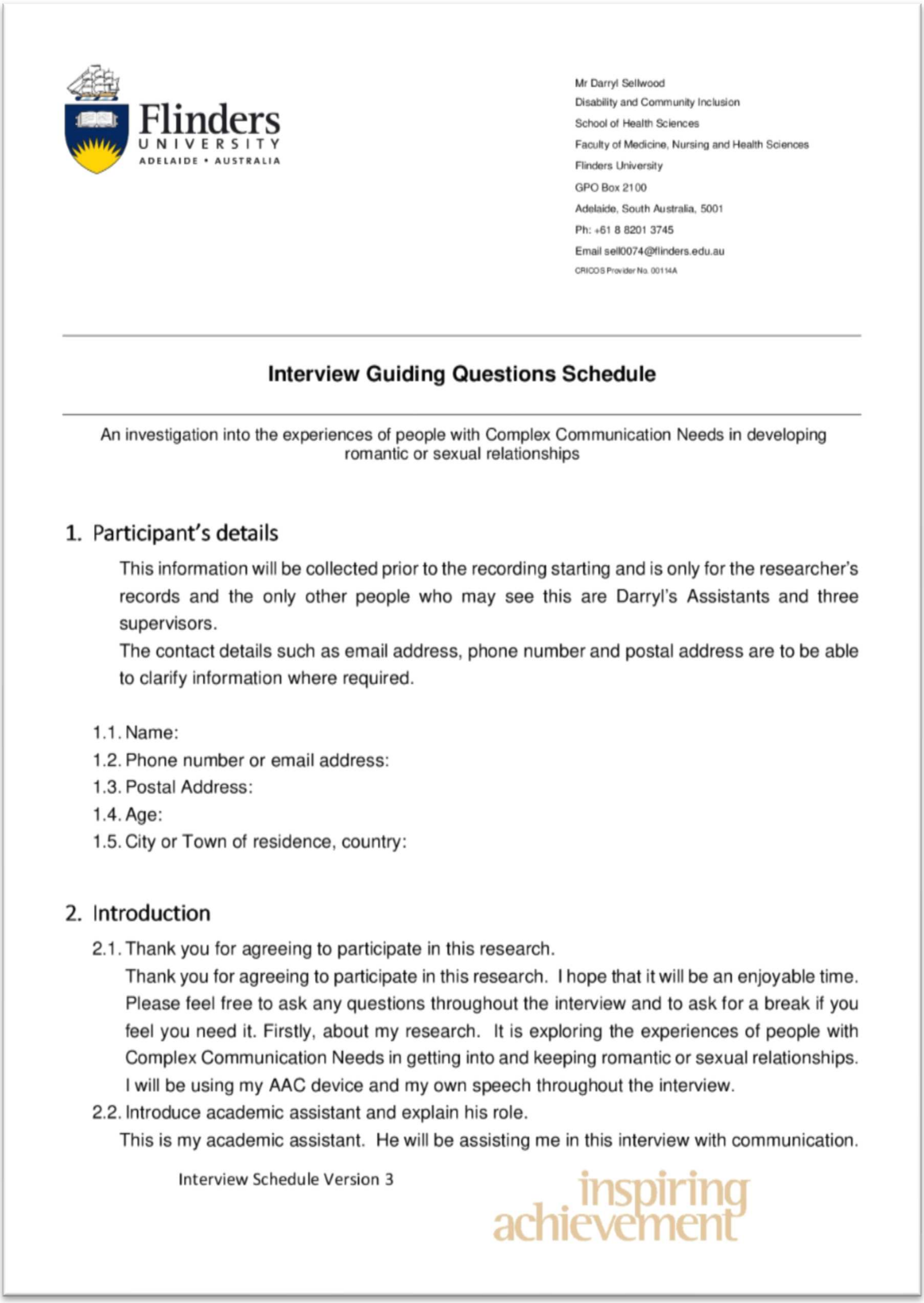
Flinders
UNIVERSITY

"An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships."

What is the study about?

This research project is supported by the Disability and Community Inclusion Unit (DCIU) of Flinders University. It investigates the experiences of people with Complex Communication Needs (CCN) in developing romantic or sexual relationships. This research is important because people with CCN are rarely asked about and supported in their love lives. Lovers with physical and communication disabilities receive little support in navigating relationships. The study explores very personal and sensitive issues which are not often discussed.

Appendix 22. Interview Guiding Questions Schedule



Mr Darryl Sellwood
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
Adelaide, South Australia, 5001
Ph: +61 8 8201 3745
Email sell0074@flinders.edu.au
CRICOS Provider No. 00114A

Interview Guiding Questions Schedule

An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships

1. Participant's details

This information will be collected prior to the recording starting and is only for the researcher's records and the only other people who may see this are Darryl's Assistants and three supervisors.

The contact details such as email address, phone number and postal address are to be able to clarify information where required.

1.1. Name:
1.2. Phone number or email address:
1.3. Postal Address:
1.4. Age:
1.5. City or Town of residence, country:

2. Introduction

2.1. Thank you for agreeing to participate in this research.

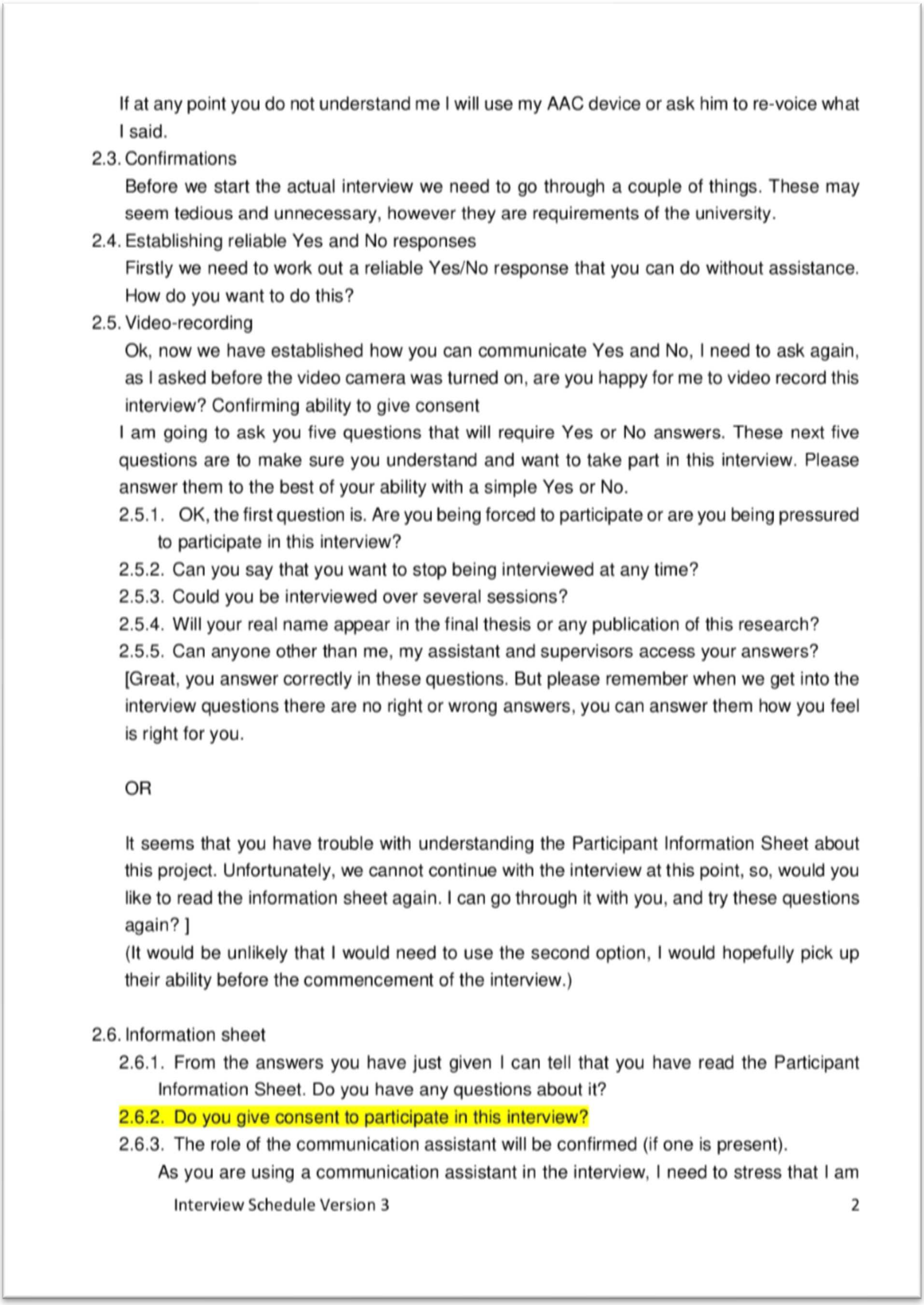
Thank you for agreeing to participate in this research. I hope that it will be an enjoyable time. Please feel free to ask any questions throughout the interview and to ask for a break if you feel you need it. Firstly, about my research. It is exploring the experiences of people with Complex Communication Needs in getting into and keeping romantic or sexual relationships. I will be using my AAC device and my own speech throughout the interview.

2.2. Introduce academic assistant and explain his role.

This is my academic assistant. He will be assisting me in this interview with communication.

Interview Schedule Version 3

inspiring achievement



If at any point you do not understand me I will use my AAC device or ask him to re-voice what I said.

2.3. Confirmations

Before we start the actual interview we need to go through a couple of things. These may seem tedious and unnecessary, however they are requirements of the university.

2.4. Establishing reliable Yes and No responses

Firstly we need to work out a reliable Yes/No response that you can do without assistance. How do you want to do this?

2.5. Video-recording

Ok, now we have established how you can communicate Yes and No, I need to ask again, as I asked before the video camera was turned on, are you happy for me to video record this interview? Confirming ability to give consent

I am going to ask you five questions that will require Yes or No answers. These next five questions are to make sure you understand and want to take part in this interview. Please answer them to the best of your ability with a simple Yes or No.

2.5.1. OK, the first question is. Are you being forced to participate or are you being pressured to participate in this interview?
2.5.2. Can you say that you want to stop being interviewed at any time?
2.5.3. Could you be interviewed over several sessions?
2.5.4. Will your real name appear in the final thesis or any publication of this research?
2.5.5. Can anyone other than me, my assistant and supervisors access your answers?

[Great, you answer correctly in these questions. But please remember when we get into the interview questions there are no right or wrong answers, you can answer them how you feel is right for you.

OR

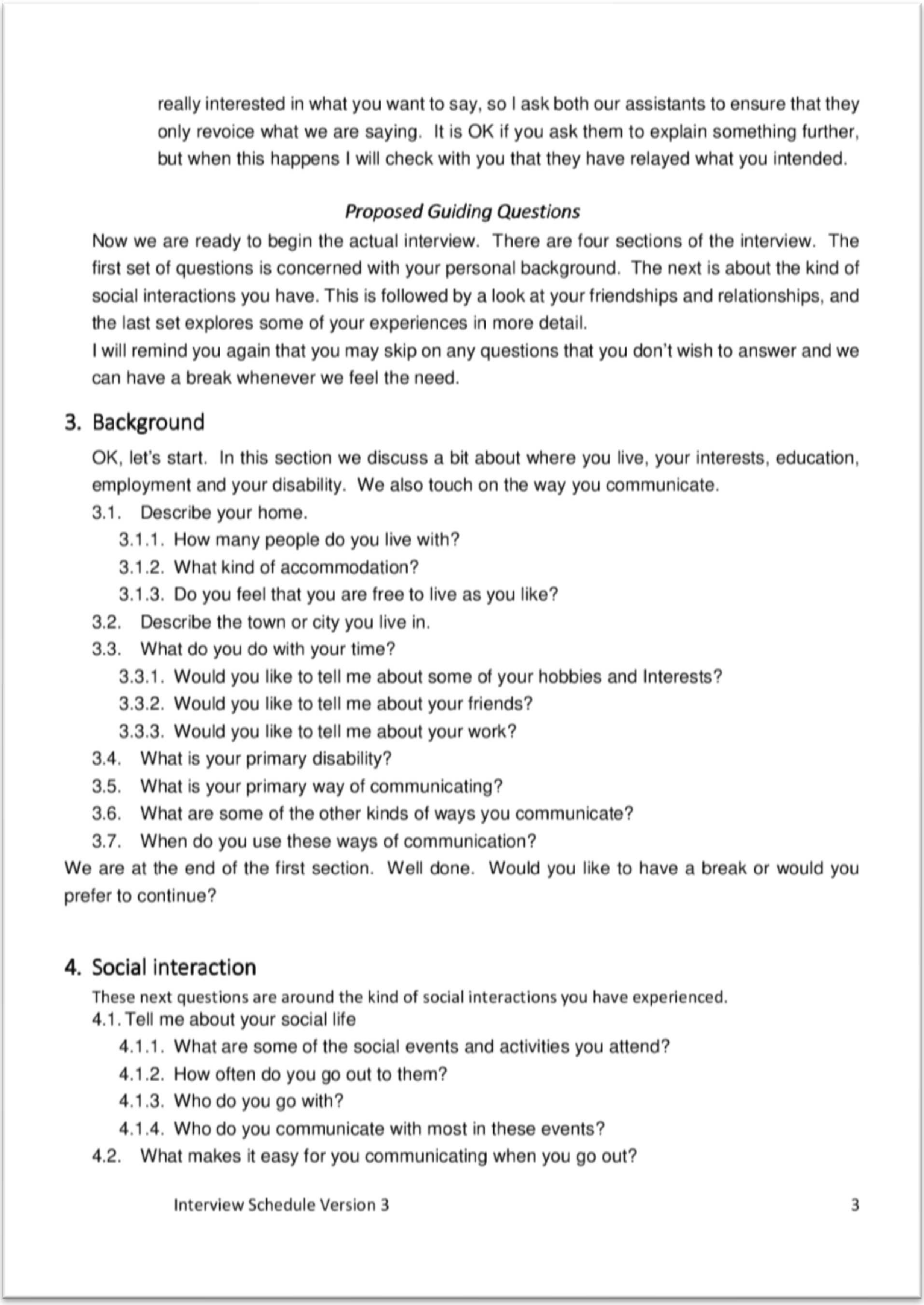
It seems that you have trouble with understanding the Participant Information Sheet about this project. Unfortunately, we cannot continue with the interview at this point, so, would you like to read the information sheet again. I can go through it with you, and try these questions again?]

(It would be unlikely that I would need to use the second option, I would hopefully pick up their ability before the commencement of the interview.)

2.6. Information sheet

2.6.1. From the answers you have just given I can tell that you have read the Participant Information Sheet. Do you have any questions about it?
2.6.2. Do you give consent to participate in this interview?
2.6.3. The role of the communication assistant will be confirmed (if one is present).

As you are using a communication assistant in the interview, I need to stress that I am



really interested in what you want to say, so I ask both our assistants to ensure that they only revoice what we are saying. It is OK if you ask them to explain something further, but when this happens I will check with you that they have relayed what you intended.

Proposed Guiding Questions

Now we are ready to begin the actual interview. There are four sections of the interview. The first set of questions is concerned with your personal background. The next is about the kind of social interactions you have. This is followed by a look at your friendships and relationships, and the last set explores some of your experiences in more detail.
I will remind you again that you may skip on any questions that you don't wish to answer and we can have a break whenever we feel the need.

3. Background

OK, let's start. In this section we discuss a bit about where you live, your interests, education, employment and your disability. We also touch on the way you communicate.

3.1. Describe your home.
  3.1.1. How many people do you live with?
  3.1.2. What kind of accommodation?
  3.1.3. Do you feel that you are free to live as you like?
3.2. Describe the town or city you live in.
3.3. What do you do with your time?
  3.3.1. Would you like to tell me about some of your hobbies and Interests?
  3.3.2. Would you like to tell me about your friends?
  3.3.3. Would you like to tell me about your work?
3.4. What is your primary disability?
3.5. What is your primary way of communicating?
3.6. What are some of the other kinds of ways you communicate?
3.7. When do you use these ways of communication?

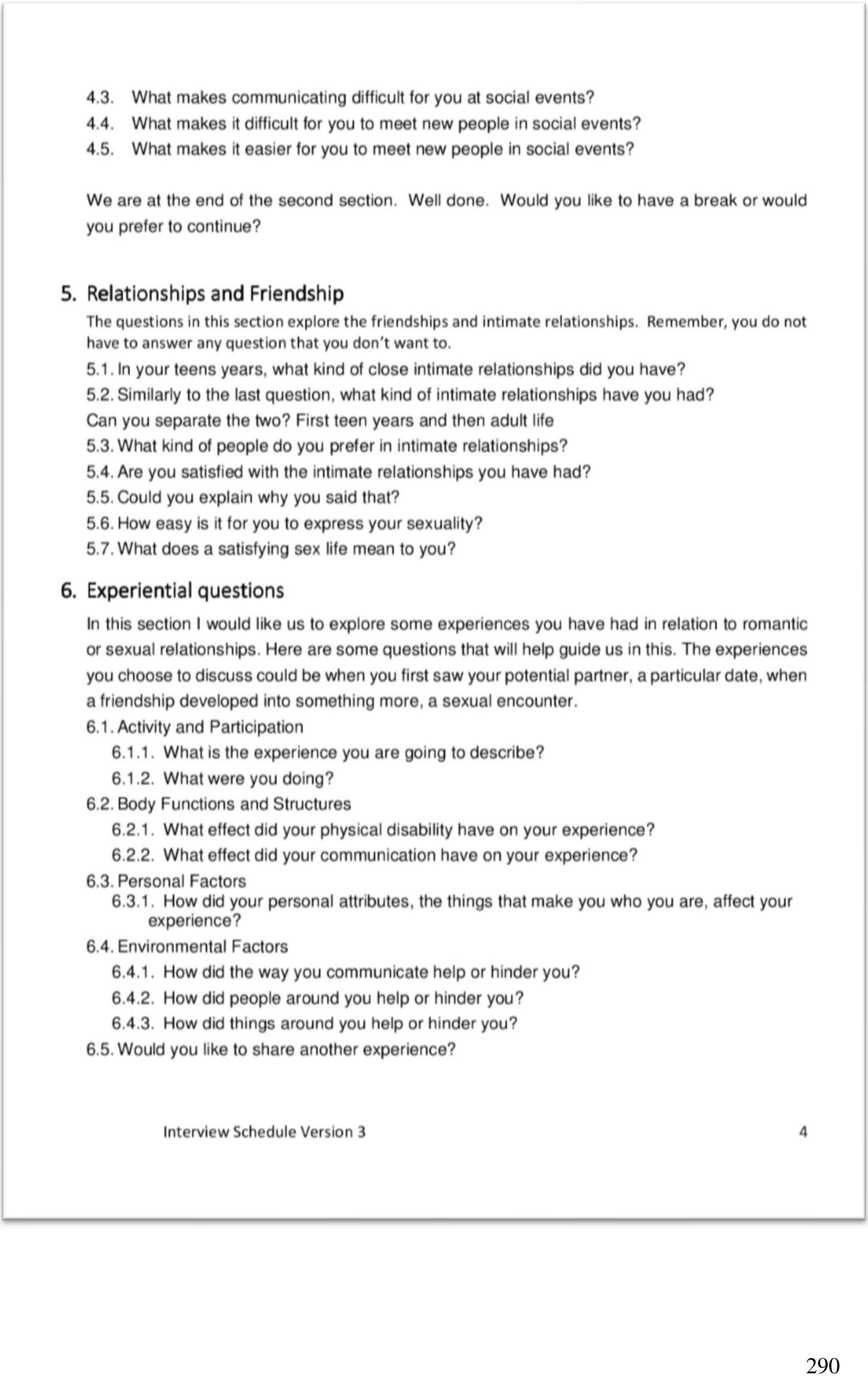
We are at the end of the first section. Well done. Would you like to have a break or would you prefer to continue?

4. Social interaction

These next questions are around the kind of social interactions you have experienced.

4.1. Tell me about your social life
  4.1.1. What are some of the social events and activities you attend?
  4.1.2. How often do you go out to them?
  4.1.3. Who do you go with?
  4.1.4. Who do you communicate with most in these events?
4.2. What makes it easy for you communicating when you go out?

Interview Schedule Version 3 3



4.3. What makes communicating difficult for you at social events?
4.4. What makes it difficult for you to meet new people in social events?
4.5. What makes it easier for you to meet new people in social events?

We are at the end of the second section. Well done. Would you like to have a break or would you prefer to continue?

5. Relationships and Friendship

The questions in this section explore the friendships and intimate relationships. Remember, you do not have to answer any question that you don't want to.

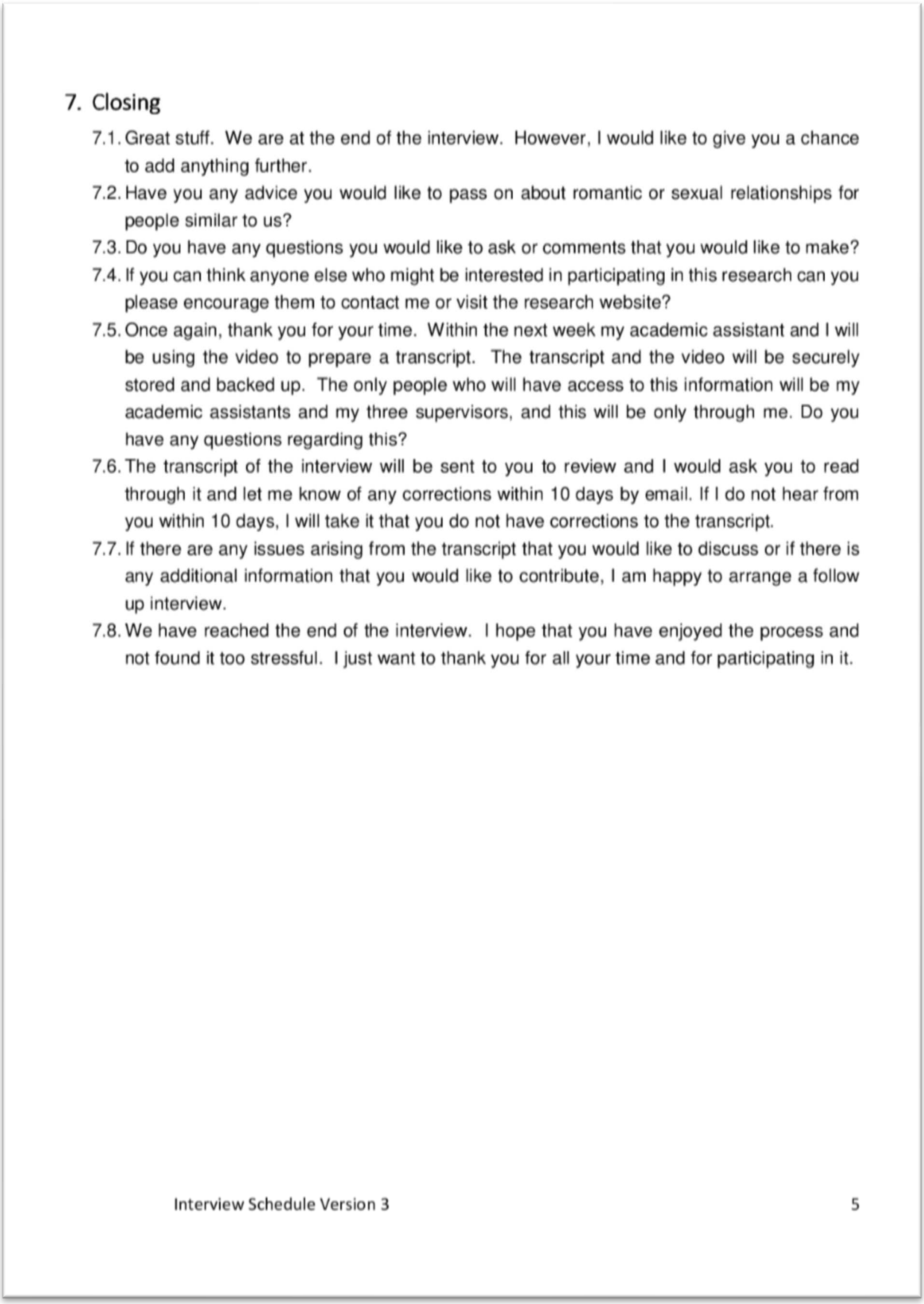
5.1. In your teens years, what kind of close intimate relationships did you have?
5.2. Similarly to the last question, what kind of intimate relationships have you had?
Can you separate the two? First teen years and then adult life
5.3. What kind of people do you prefer in intimate relationships?
5.4. Are you satisfied with the intimate relationships you have had?
5.5. Could you explain why you said that?
5.6. How easy is it for you to express your sexuality?
5.7. What does a satisfying sex life mean to you?

6. Experiential questions

In this section I would like us to explore some experiences you have had in relation to romantic or sexual relationships. Here are some questions that will help guide us in this. The experiences you choose to discuss could be when you first saw your potential partner, a particular date, when a friendship developed into something more, a sexual encounter.

6.1. Activity and Participation
    6.1.1. What is the experience you are going to describe?
    6.1.2. What were you doing?
6.2. Body Functions and Structures
    6.2.1. What effect did your physical disability have on your experience?
    6.2.2. What effect did your communication have on your experience?
6.3. Personal Factors
    6.3.1. How did your personal attributes, the things that make you who you are, affect your experience?
6.4. Environmental Factors
    6.4.1. How did the way you communicate help or hinder you?
    6.4.2. How did people around you help or hinder you?
    6.4.3. How did things around you help or hinder you?
6.5. Would you like to share another experience?

Interview Schedule Version 3 4



7. Closing

7.1. Great stuff. We are at the end of the interview. However, I would like to give you a chance to add anything further.

7.2. Have you any advice you would like to pass on about romantic or sexual relationships for people similar to us?

7.3. Do you have any questions you would like to ask or comments that you would like to make?

7.4. If you can think anyone else who might be interested in participating in this research can you please encourage them to contact me or visit the research website?

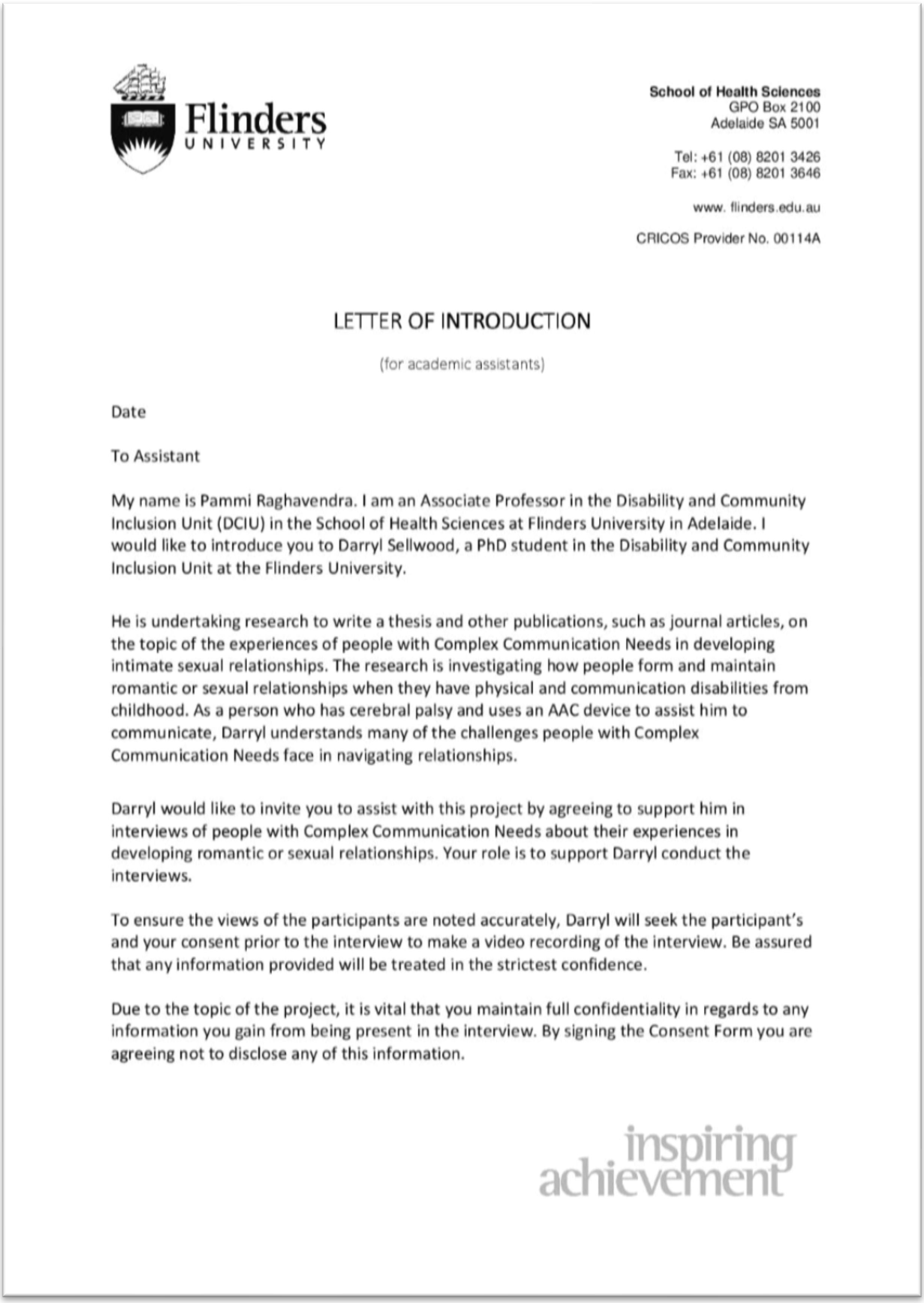
7.5. Once again, thank you for your time. Within the next week my academic assistant and I will be using the video to prepare a transcript. The transcript and the video will be securely stored and backed up. The only people who will have access to this information will be my academic assistants and my three supervisors, and this will be only through me. Do you have any questions regarding this?

7.6. The transcript of the interview will be sent to you to review and I would ask you to read through it and let me know of any corrections within 10 days by email. If I do not hear from you within 10 days, I will take it that you do not have corrections to the transcript.

7.7. If there are any issues arising from the transcript that you would like to discuss or if there is any additional information that you would like to contribute, I am happy to arrange a follow up interview.

7.8. We have reached the end of the interview. I hope that you have enjoyed the process and not found it too stressful. I just want to thank you for all your time and for participating in it.

Appendix 23. Letter of Introduction to academic assistants



Flinders
UNIVERSITY

School of Health Sciences
GPO Box 2100
Adelaide SA 5001

Tel: +61 (08) 8201 3426
Fax: +61 (08) 8201 3646

www. flinders.edu.au

CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

(for academic assistants)

Date

To Assistant

My name is Pammi Raghavendra. I am an Associate Professor in the Disability and Community Inclusion Unit (DCIU) in the School of Health Sciences at Flinders University in Adelaide. I would like to introduce you to Darryl Sellwood, a PhD student in the Disability and Community Inclusion Unit at the Flinders University.

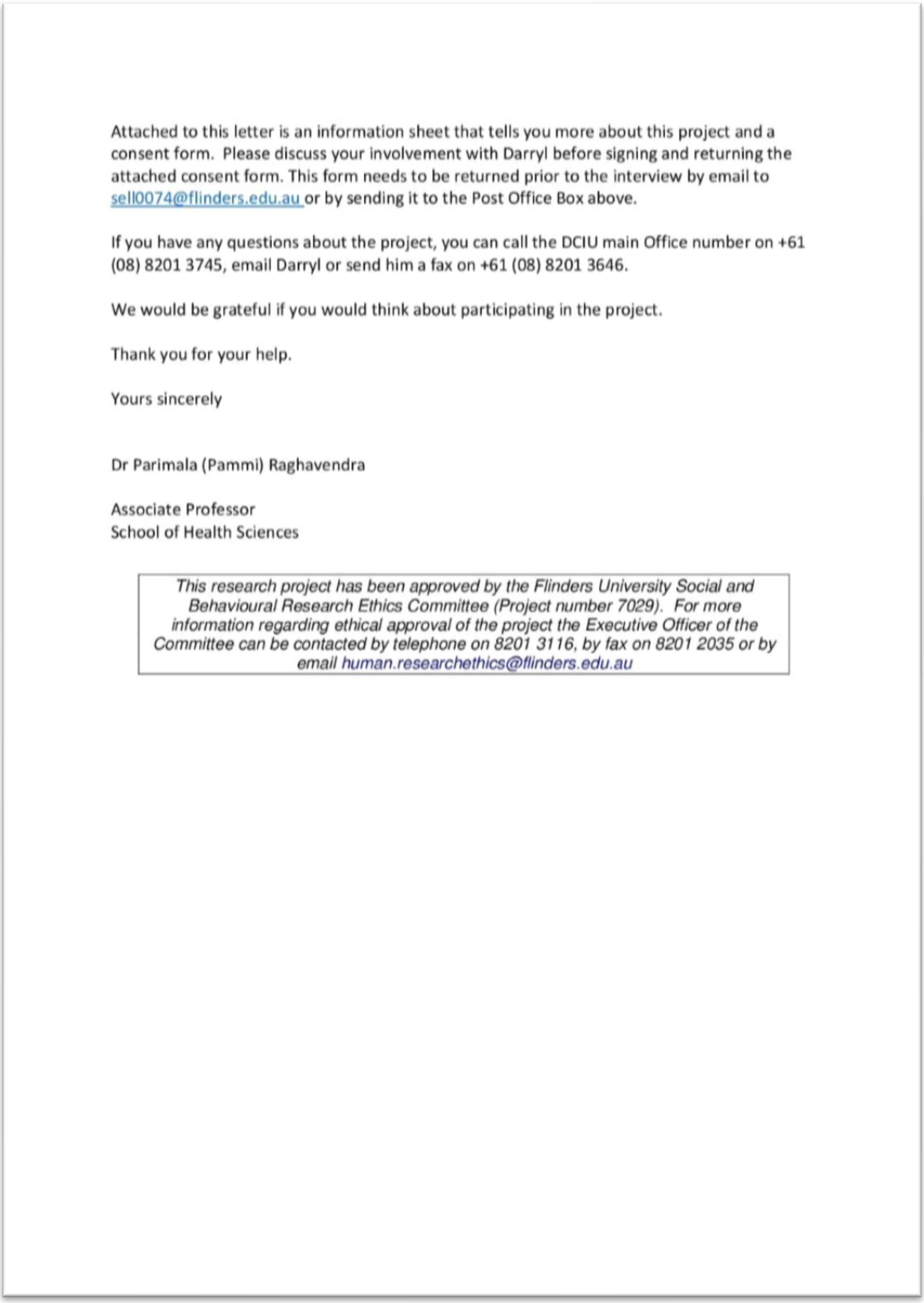
He is undertaking research to write a thesis and other publications, such as journal articles, on the topic of the experiences of people with Complex Communication Needs in developing intimate sexual relationships. The research is investigating how people form and maintain romantic or sexual relationships when they have physical and communication disabilities from childhood. As a person who has cerebral palsy and uses an AAC device to assist him to communicate, Darryl understands many of the challenges people with Complex Communication Needs face in navigating relationships.

Darryl would like to invite you to assist with this project by agreeing to support him in interviews of people with Complex Communication Needs about their experiences in developing romantic or sexual relationships. Your role is to support Darryl conduct the interviews.

To ensure the views of the participants are noted accurately, Darryl will seek the participant's and your consent prior to the interview to make a video recording of the interview. Be assured that any information provided will be treated in the strictest confidence.

Due to the topic of the project, it is vital that you maintain full confidentiality in regards to any information you gain from being present in the interview. By signing the Consent Form you are agreeing not to disclose any of this information.

inspiring
achievement



Attached to this letter is an information sheet that tells you more about this project and a consent form. Please discuss your involvement with Darryl before signing and returning the attached consent form. This form needs to be returned prior to the interview by email to sell0074@flinders.edu.au or by sending it to the Post Office Box above.

If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email Darryl or send him a fax on +61 (08) 8201 3646.

We would be grateful if you would think about participating in the project.

Thank you for your help.

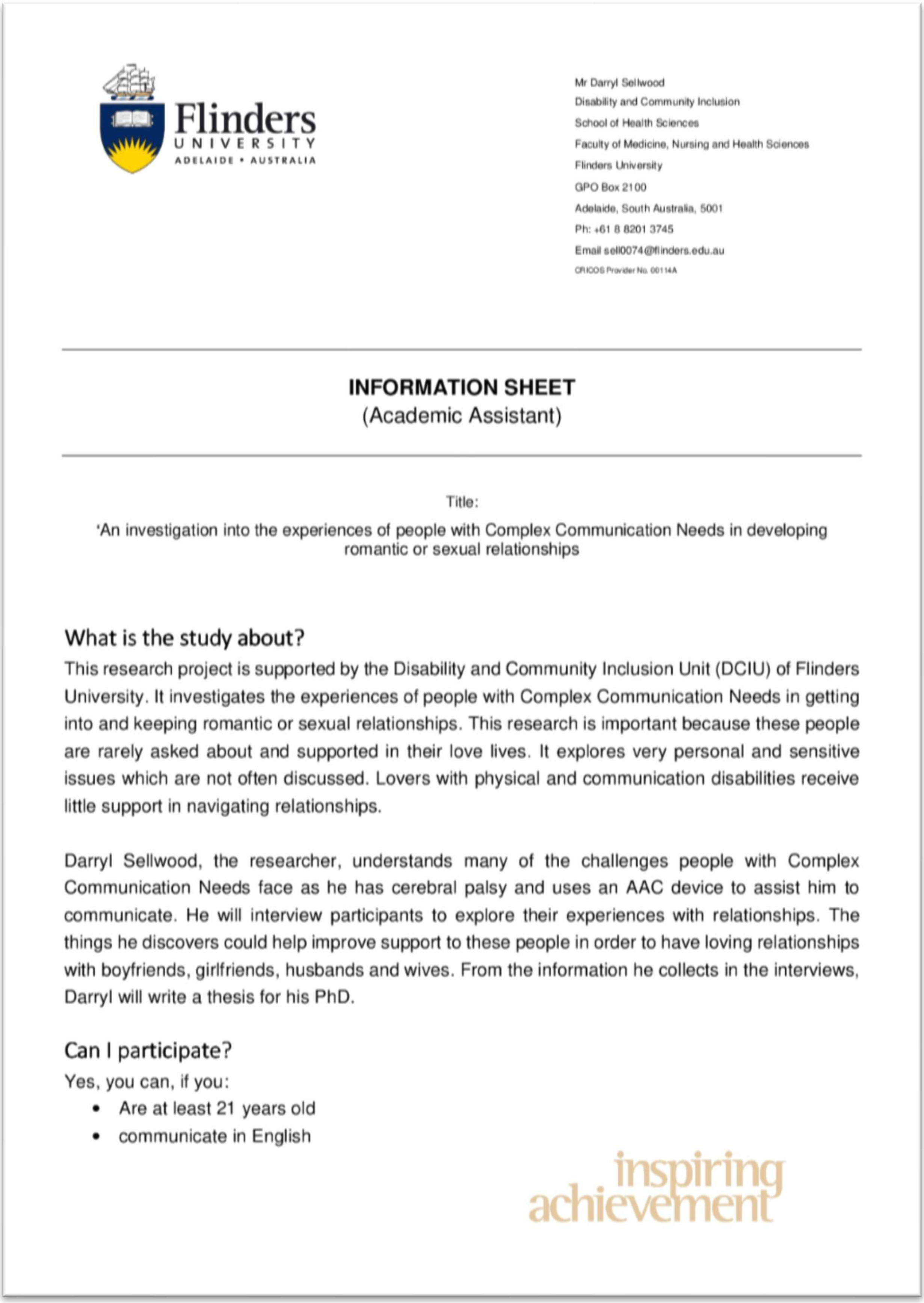
Yours sincerely

Dr Parimala (Pammi) Raghavendra

Associate Professor
School of Health Sciences

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7029). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 24. Academic Assistant Information Sheet



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Mr Darryl Sellwood
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
Adelaide, South Australia, 5001
Ph: +61 8 8201 3745
Email sell0074@flinders.edu.au
CRICOS Provider No. 00114A

INFORMATION SHEET
(Academic Assistant)

Title:

'An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships

What is the study about?

This research project is supported by the Disability and Community Inclusion Unit (DCIU) of Flinders University. It investigates the experiences of people with Complex Communication Needs in getting into and keeping romantic or sexual relationships. This research is important because these people are rarely asked about and supported in their love lives. It explores very personal and sensitive issues which are not often discussed. Lovers with physical and communication disabilities receive little support in navigating relationships.

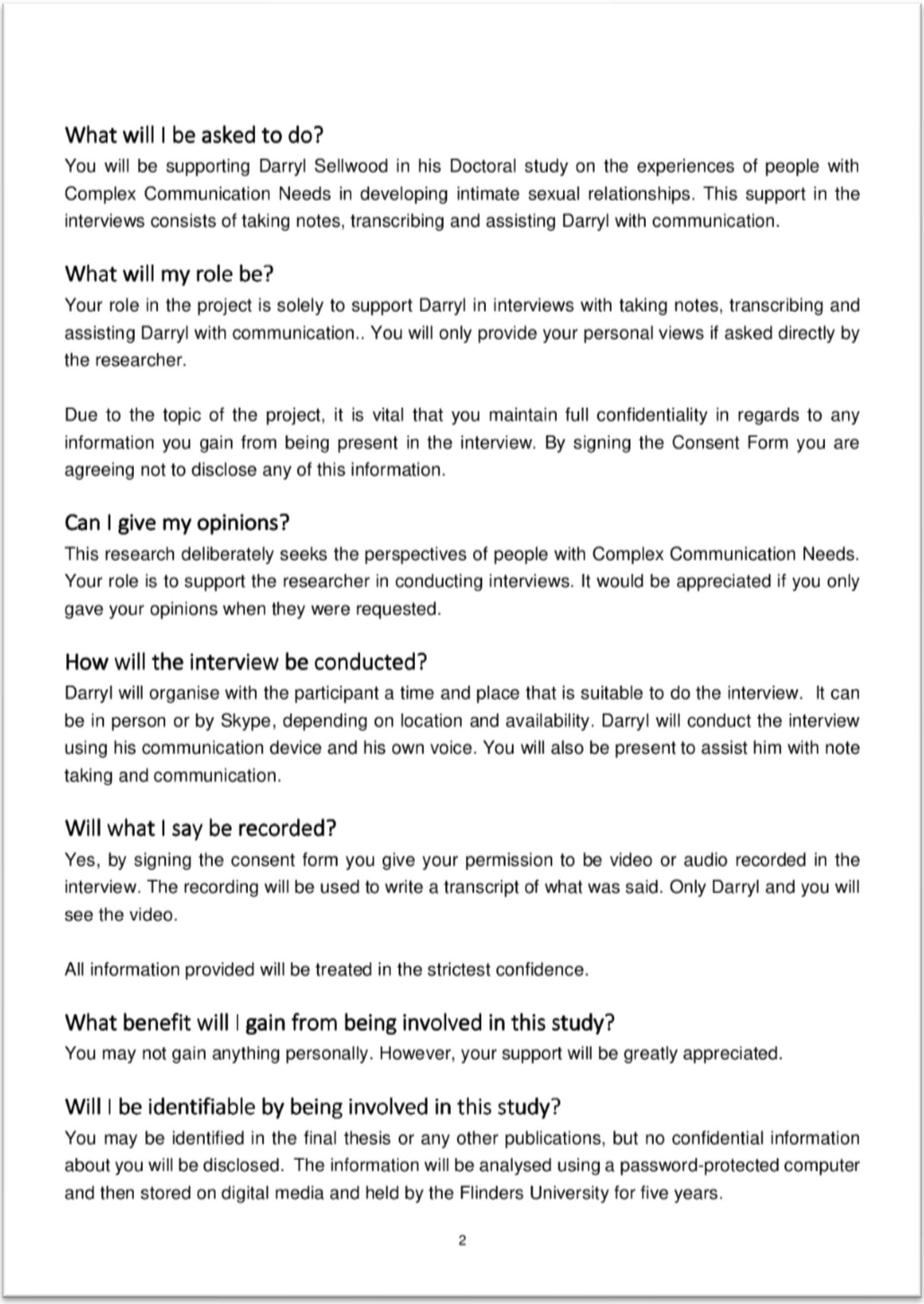
Darryl Sellwood, the researcher, understands many of the challenges people with Complex Communication Needs face as he has cerebral palsy and uses an AAC device to assist him to communicate. He will interview participants to explore their experiences with relationships. The things he discovers could help improve support to these people in order to have loving relationships with boyfriends, girlfriends, husbands and wives. From the information he collects in the interviews, Darryl will write a thesis for his PhD.

Can I participate?

Yes, you can, if you:

- Are at least 21 years old
- communicate in English

inspiring achievement



What will I be asked to do?

You will be supporting Darryl Sellwood in his Doctoral study on the experiences of people with Complex Communication Needs in developing intimate sexual relationships. This support in the interviews consists of taking notes, transcribing and assisting Darryl with communication.

What will my role be?

Your role in the project is solely to support Darryl in interviews with taking notes, transcribing and assisting Darryl with communication.. You will only provide your personal views if asked directly by the researcher.

Due to the topic of the project, it is vital that you maintain full confidentiality in regards to any information you gain from being present in the interview. By signing the Consent Form you are agreeing not to disclose any of this information.

Can I give my opinions?

This research deliberately seeks the perspectives of people with Complex Communication Needs. Your role is to support the researcher in conducting interviews. It would be appreciated if you only gave your opinions when they were requested.

How will the interview be conducted?

Darryl will organise with the participant a time and place that is suitable to do the interview. It can be in person or by Skype, depending on location and availability. Darryl will conduct the interview using his communication device and his own voice. You will also be present to assist him with note taking and communication.

Will what I say be recorded?

Yes, by signing the consent form you give your permission to be video or audio recorded in the interview. The recording will be used to write a transcript of what was said. Only Darryl and you will see the video.

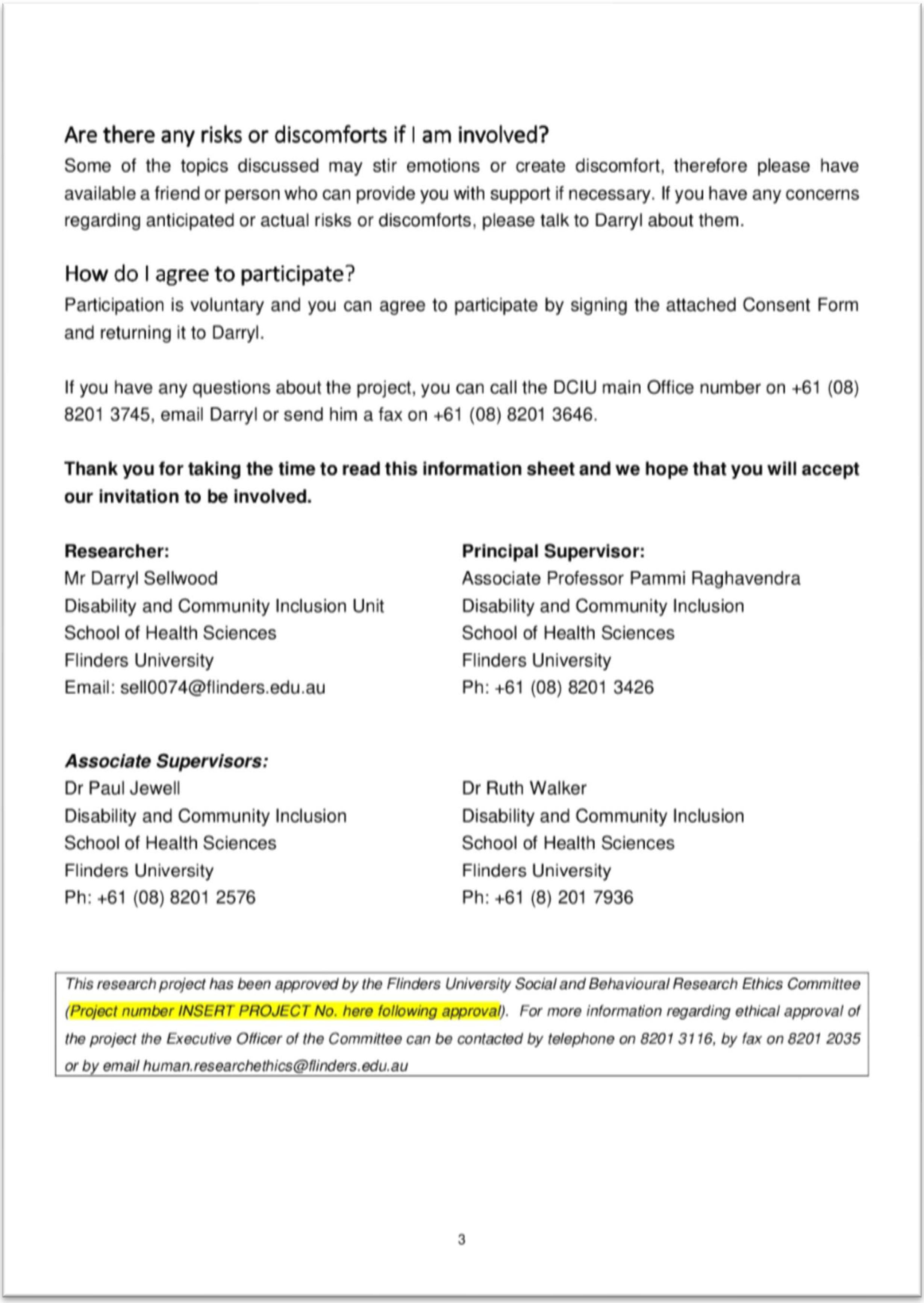
All information provided will be treated in the strictest confidence.

What benefit will I gain from being involved in this study?

You may not gain anything personally. However, your support will be greatly appreciated.

Will I be identifiable by being involved in this study?

You may be identified in the final thesis or any other publications, but no confidential information about you will be disclosed. The information will be analysed using a password-protected computer and then stored on digital media and held by the Flinders University for five years.



Are there any risks or discomforts if I am involved?

Some of the topics discussed may stir emotions or create discomfort, therefore please have available a friend or person who can provide you with support if necessary. If you have any concerns regarding anticipated or actual risks or discomforts, please talk to Darryl about them.

How do I agree to participate?

Participation is voluntary and you can agree to participate by signing the attached Consent Form and returning it to Darryl.

If you have any questions about the project, you can call the DCIU main Office number on +61 (08) 8201 3745, email Darryl or send him a fax on +61 (08) 8201 3646.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

Researcher:
Mr Darryl Sellwood
Disability and Community Inclusion Unit
School of Health Sciences
Flinders University
Email: sell0074@flinders.edu.au

Principal Supervisor:
Associate Professor Pammi Raghavendra
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (08) 8201 3426

Associate Supervisors:

Dr Paul Jewell
Disability and Community Inclusion
School of Health Sciences
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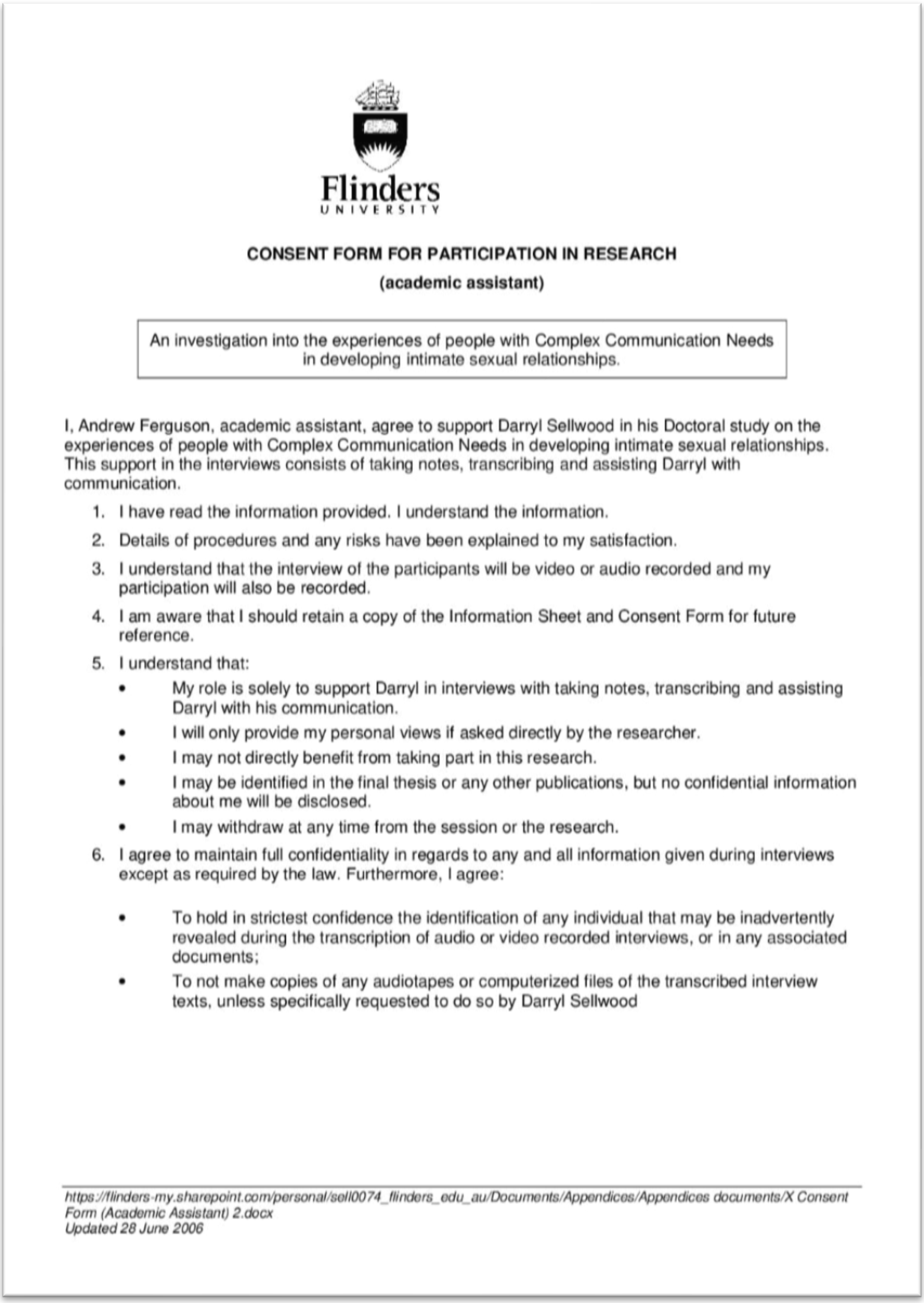
Dr Ruth Walker
Disability and Community Inclusion
School of Health Sciences
Flinders University
Ph: +61 (8) 201 7936

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number INSERT PROJECT No. here following approval). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 25. Academic Assistant Consent Form



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CONSENT FORM FOR PARTICIPATION IN RESEARCH

(academic assistant)

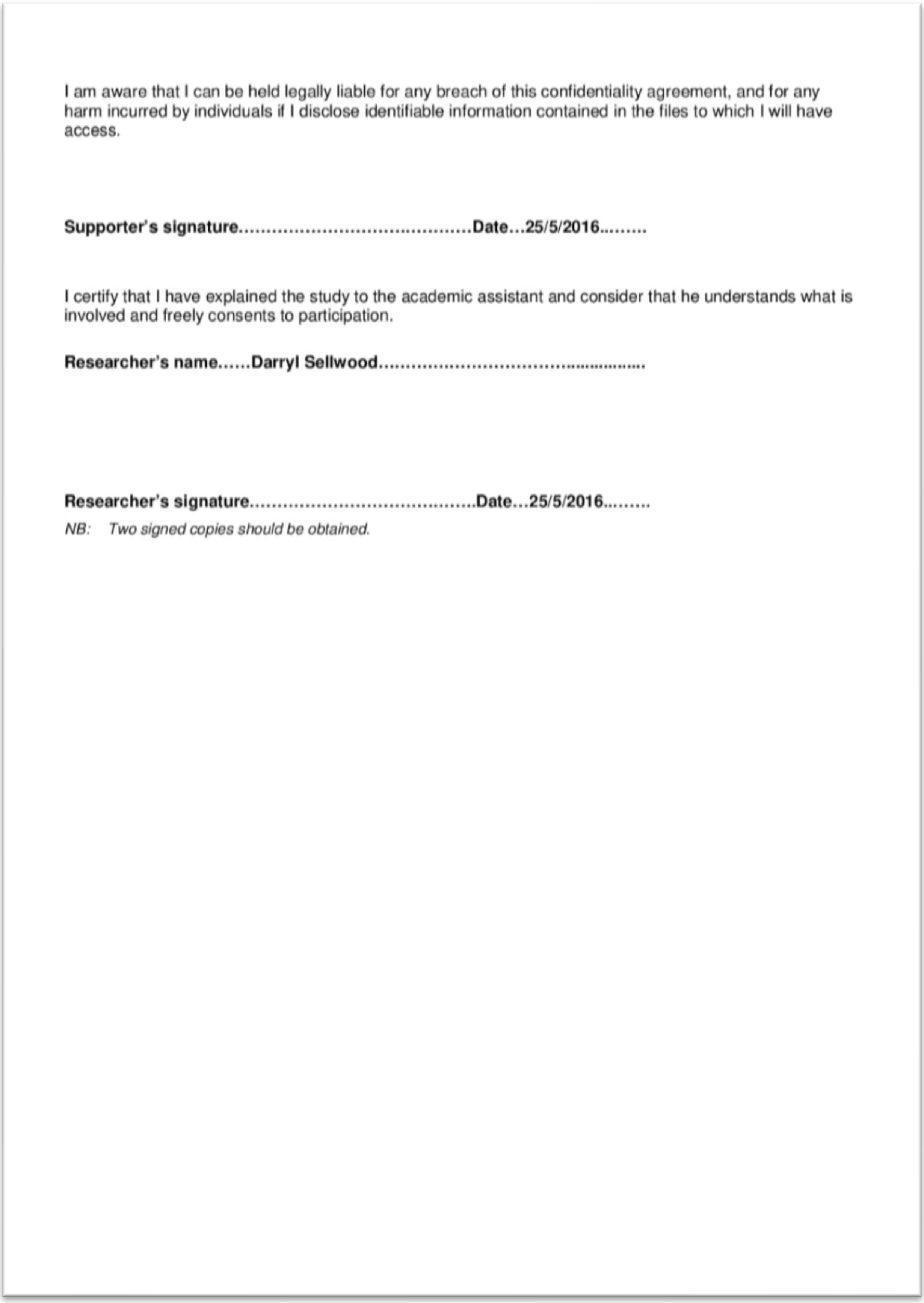
An investigation into the experiences of people with Complex Communication Needs in developing intimate sexual relationships.

I, Andrew Ferguson, academic assistant, agree to support Darryl Sellwood in his Doctoral study on the experiences of people with Complex Communication Needs in developing intimate sexual relationships. This support in the interviews consists of taking notes, transcribing and assisting Darryl with communication.

1. I have read the information provided. I understand the information.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I understand that the interview of the participants will be video or audio recorded and my participation will also be recorded.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - My role is solely to support Darryl in interviews with taking notes, transcribing and assisting Darryl with his communication.
    - I will only provide my personal views if asked directly by the researcher.
    - I may not directly benefit from taking part in this research.
    - I may be identified in the final thesis or any other publications, but no confidential information about me will be disclosed.
    - I may withdraw at any time from the session or the research.
6. I agree to maintain full confidentiality in regards to any and all information given during interviews except as required by the law. Furthermore, I agree:

    - To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio or video recorded interviews, or in any associated documents;
    - To not make copies of any audiotapes or computerized files of the transcribed interview texts, unless specifically requested to do so by Darryl Sellwood

https://flinders-my.sharepoint.com/personal/sell0074_flinders_edu_au/Documents/Appendices/Appendices documents/X Consent Form (Academic Assistant) 2.docx
Updated 28 June 2006



I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the files to which I will have access.

Supporter's signature……………………………………Date…25/5/2016...……

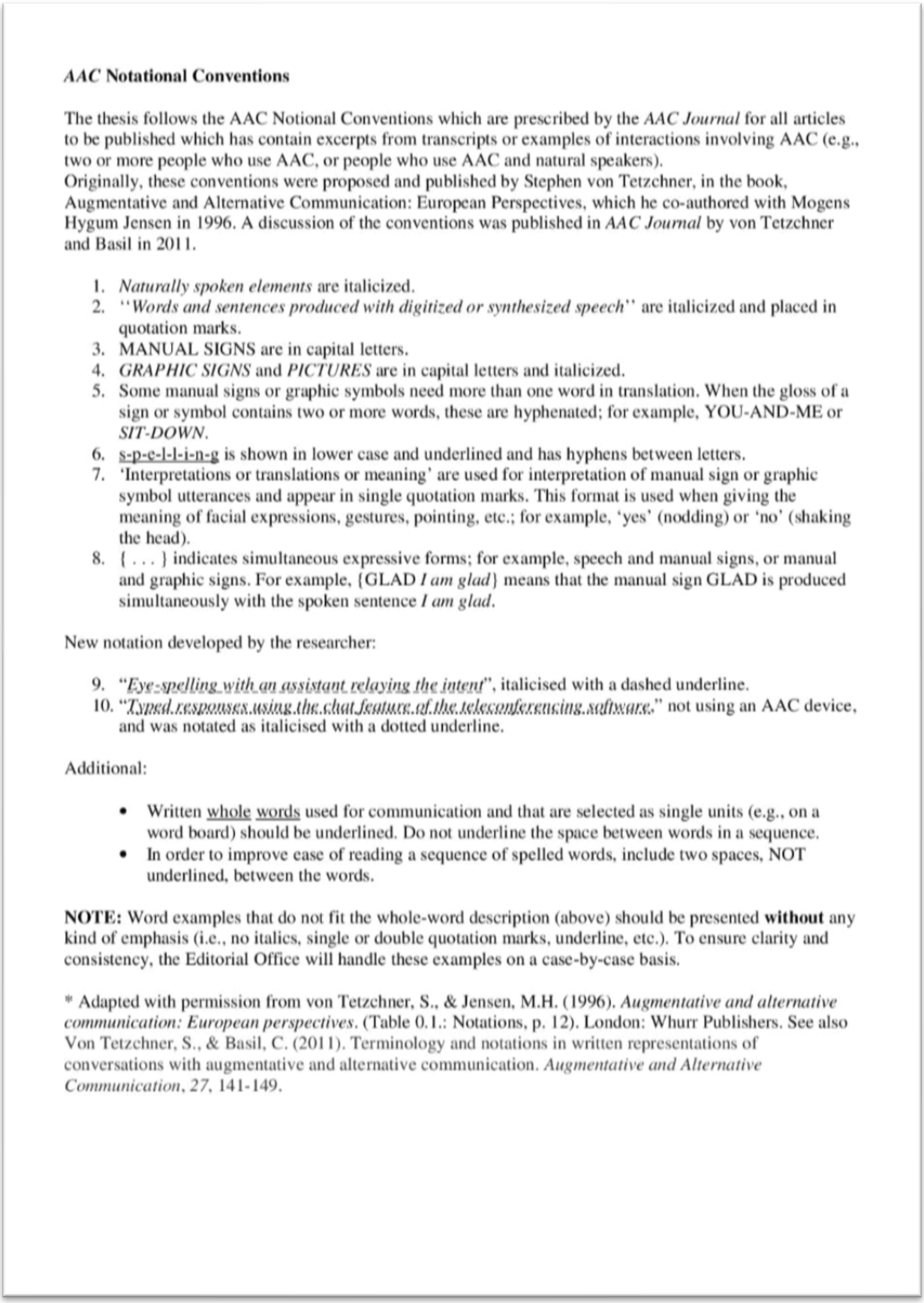
I certify that I have explained the study to the academic assistant and consider that he understands what is involved and freely consents to participation.

Researcher's name……Darryl Sellwood…………………………….............

Researcher's signature…………………………………..Date…25/5/2016...……

NB: Two signed copies should be obtained.

Appendix 26. AAC Notational Conventions



AAC Notational Conventions

The thesis follows the AAC Notional Conventions which are prescribed by the *AAC Journal* for all articles to be published which has contain excerpts from transcripts or examples of interactions involving AAC (e.g., two or more people who use AAC, or people who use AAC and natural speakers).
Originally, these conventions were proposed and published by Stephen von Tetzchner, in the book, Augmentative and Alternative Communication: European Perspectives, which he co-authored with Mogens Hygum Jensen in 1996. A discussion of the conventions was published in *AAC Journal* by von Tetzchner and Basil in 2011.

1. *Naturally spoken elements* are italicized.
2. ''*Words and sentences produced with digitized or synthesized speech*'' are italicized and placed in quotation marks.
3. MANUAL SIGNS are in capital letters.
4. *GRAPHIC SIGNS* and *PICTURES* are in capital letters and italicized.
5. Some manual signs or graphic symbols need more than one word in translation. When the gloss of a sign or symbol contains two or more words, these are hyphenated; for example, YOU-AND-ME or *SIT-DOWN*.
6. s-p-e-l-l-i-n-g is shown in lower case and underlined and has hyphens between letters.
7. 'Interpretations or translations or meaning' are used for interpretation of manual sign or graphic symbol utterances and appear in single quotation marks. This format is used when giving the meaning of facial expressions, gestures, pointing, etc.; for example, 'yes' (nodding) or 'no' (shaking the head).
8. { . . . } indicates simultaneous expressive forms; for example, speech and manual signs, or manual and graphic signs. For example, {GLAD *I am glad*} means that the manual sign GLAD is produced simultaneously with the spoken sentence *I am glad*.

New notation developed by the researcher:

9. "*Eye-spelling with an assistant relaying the intent*", italicised with a dashed underline.
10. "*Typed responses using the chat feature of the teleconferencing software*," not using an AAC device, and was notated as italicised with a dotted underline.

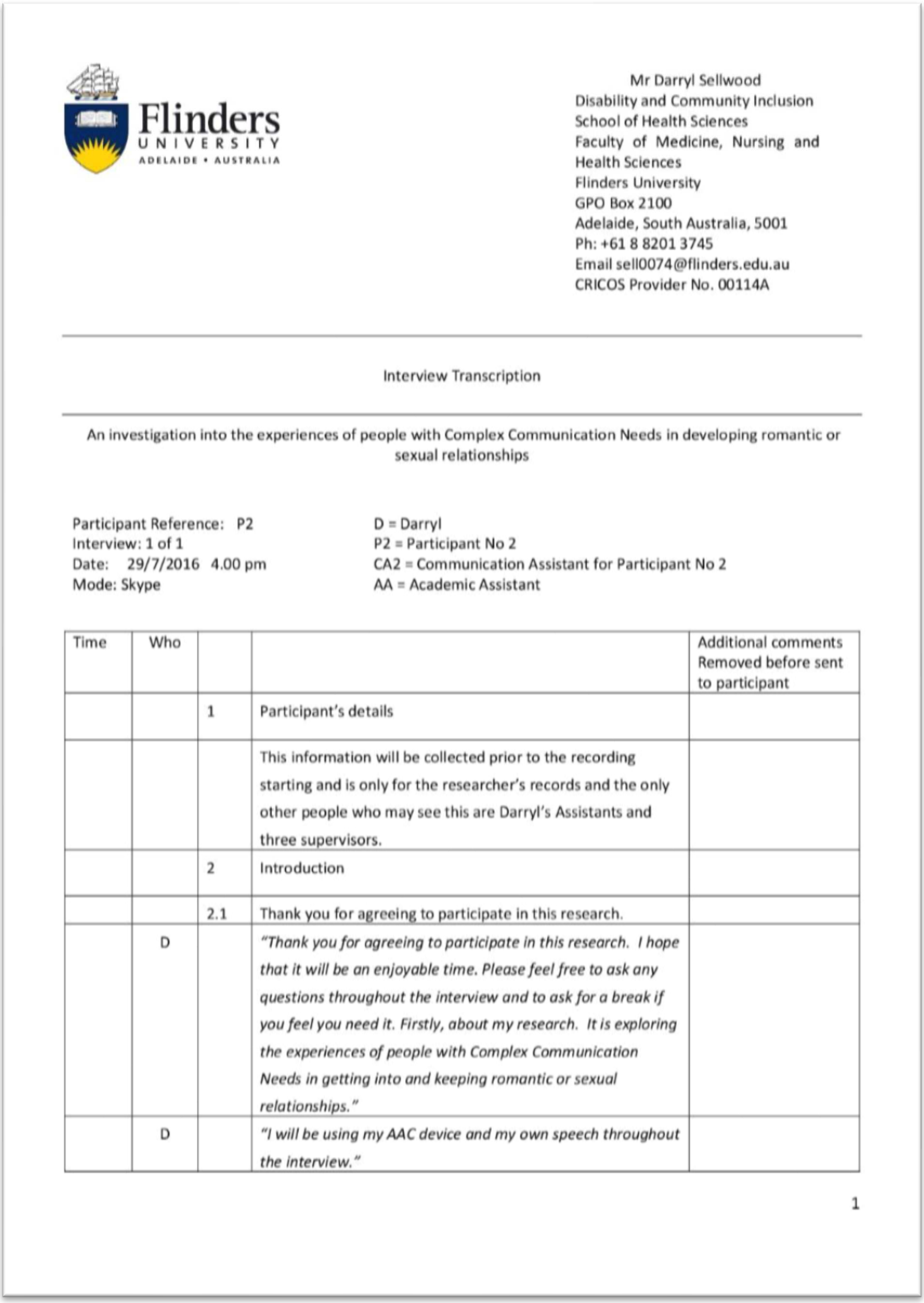
Additional:

- Written whole words used for communication and that are selected as single units (e.g., on a word board) should be underlined. Do not underline the space between words in a sequence.
- In order to improve ease of reading a sequence of spelled words, include two spaces, NOT underlined, between the words.

NOTE: Word examples that do not fit the whole-word description (above) should be presented **without** any kind of emphasis (i.e., no italics, single or double quotation marks, underline, etc.). To ensure clarity and consistency, the Editorial Office will handle these examples on a case-by-case basis.

* Adapted with permission from von Tetzchner, S., & Jensen, M.H. (1996). *Augmentative and alternative communication: European perspectives*. (Table 0.1.: Notations, p. 12). London: Whurr Publishers. See also Von Tetzchner, S., & Basil, C. (2011). Terminology and notations in written representations of conversations with augmentative and alternative communication. *Augmentative and Alternative Communication*, *27*, 141-149.

Appendix 27. Transcript template



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Email sell0074@flinders.edu.au
CRICOS Provider No. 00114A

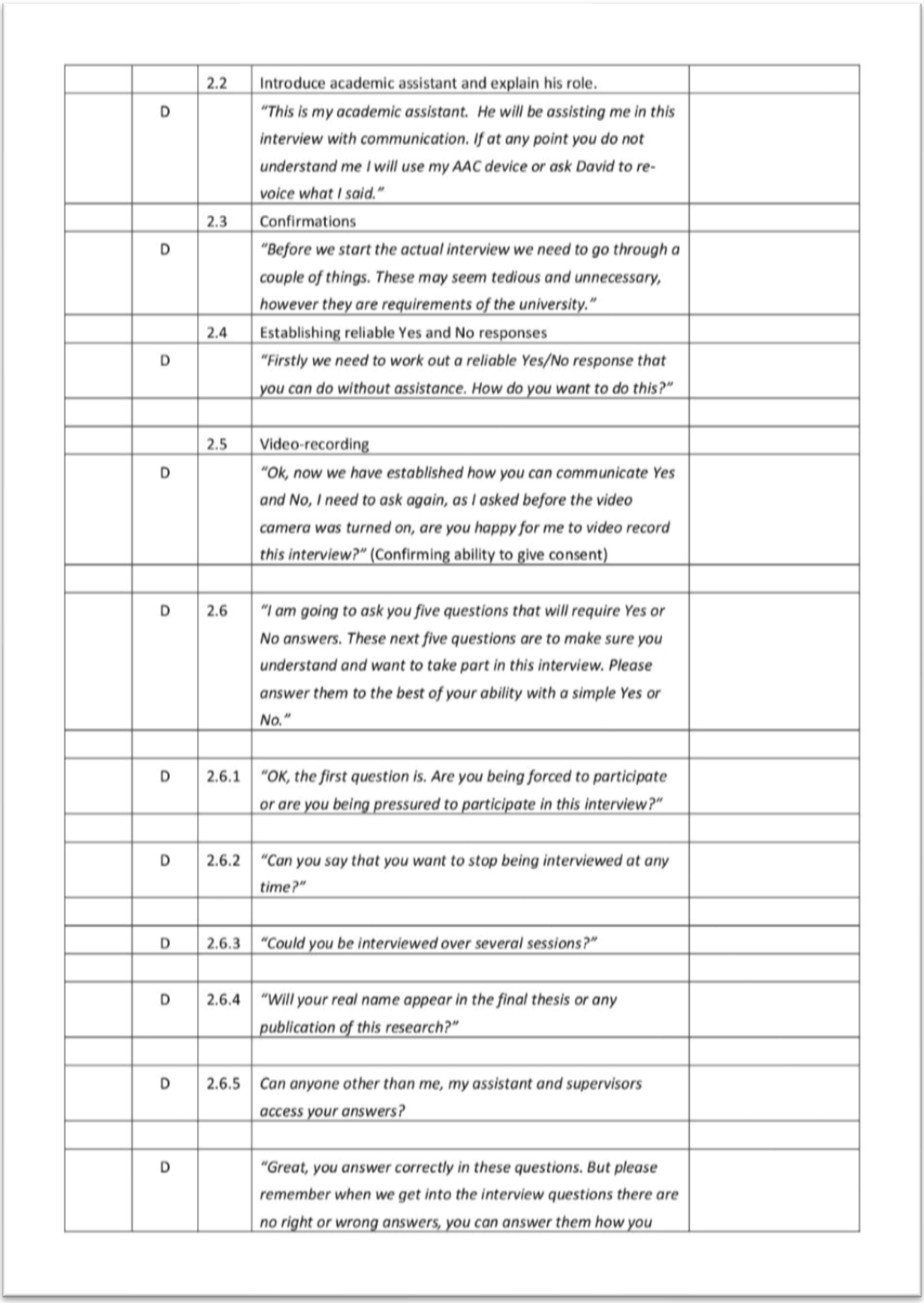
Interview Transcription

An investigation into the experiences of people with Complex Communication Needs in developing romantic or sexual relationships

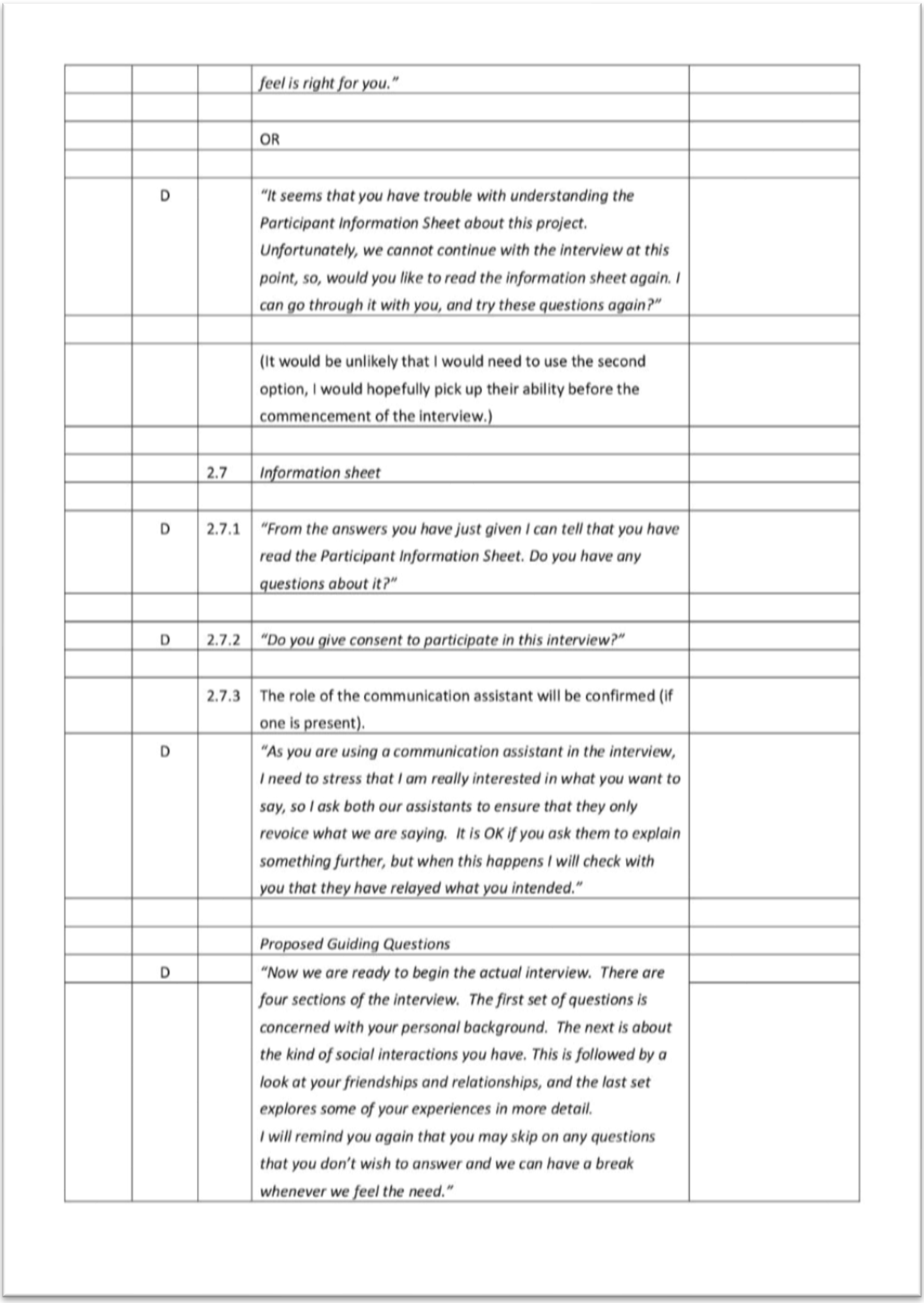
Participant Reference: P2
Interview: 1 of 1
Date: 29/7/2016 4.00 pm
Mode: Skype

D = Darryl
P2 = Participant No 2
CA2 = Communication Assistant for Participant No 2
AA = Academic Assistant

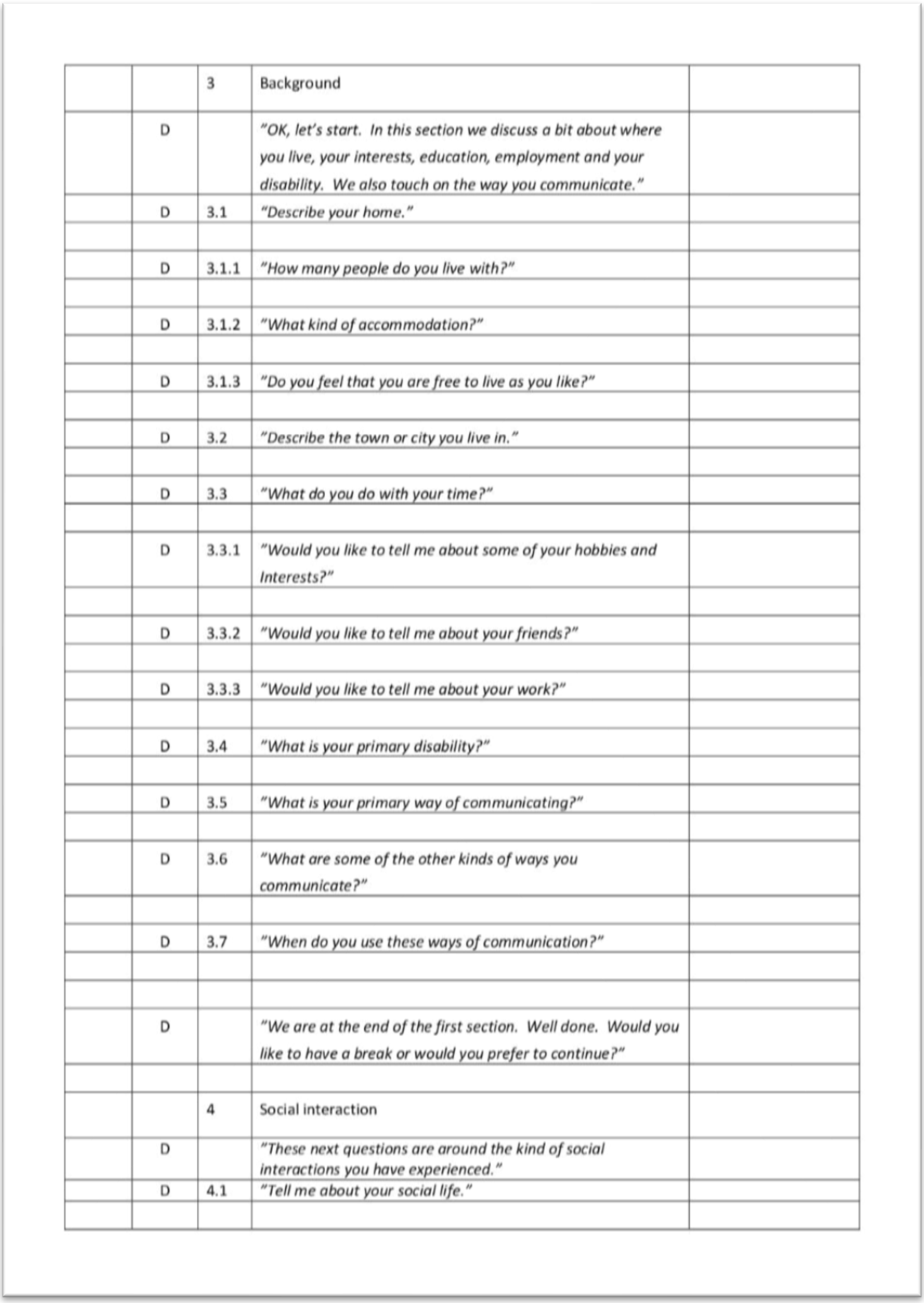
Time	Who			Additional comments Removed before sent to participant
		1	Participant's details	
			This information will be collected prior to the recording starting and is only for the researcher's records and the only other people who may see this are Darryl's Assistants and three supervisors.	
		2	Introduction	
		2.1	Thank you for agreeing to participate in this research.	
	D		*"Thank you for agreeing to participate in this research. I hope that it will be an enjoyable time. Please feel free to ask any questions throughout the interview and to ask for a break if you feel you need it. Firstly, about my research. It is exploring the experiences of people with Complex Communication Needs in getting into and keeping romantic or sexual relationships."*	
	D		*"I will be using my AAC device and my own speech throughout the interview."*	



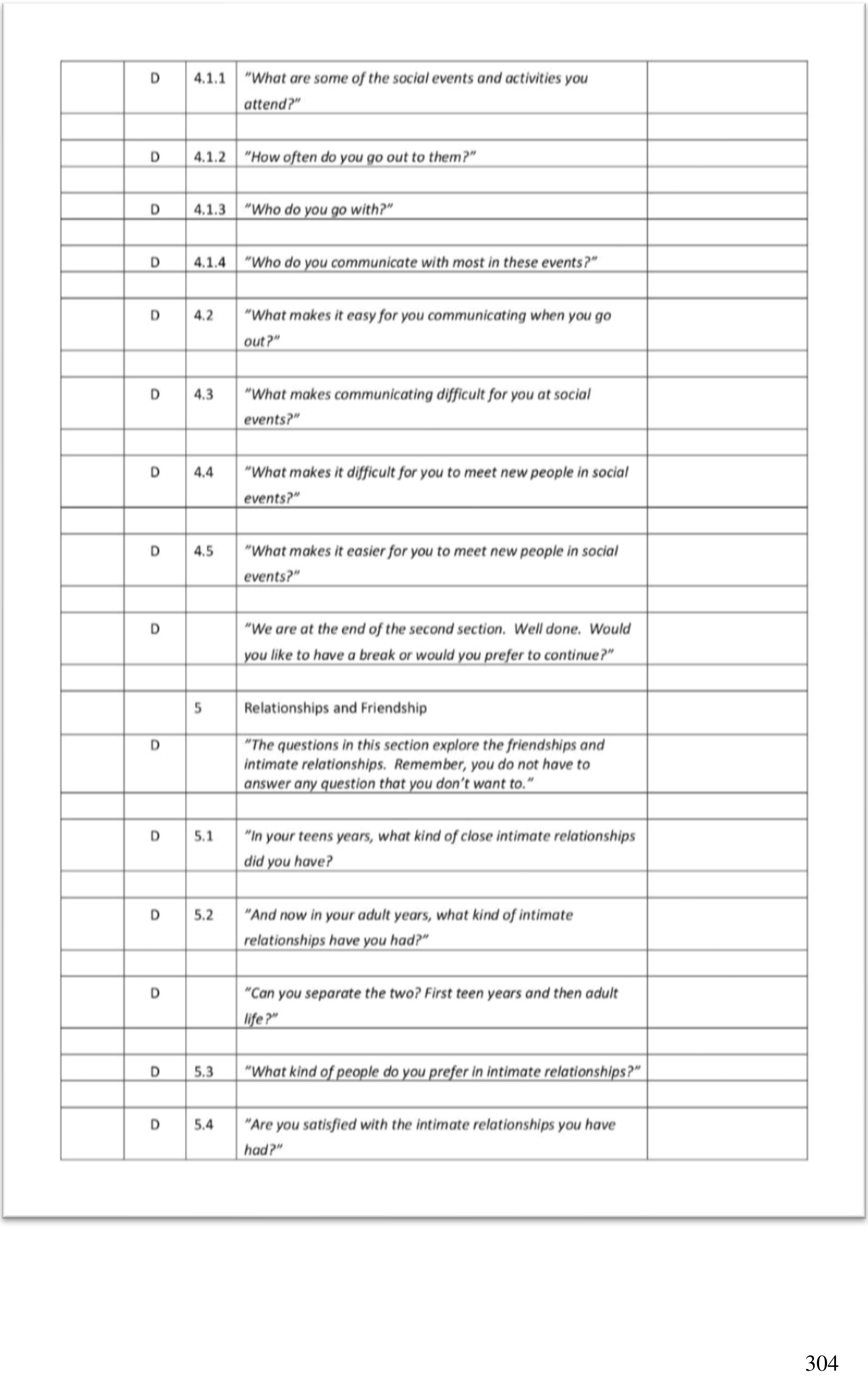
		2.2	Introduce academic assistant and explain his role.	
	D		*"This is my academic assistant. He will be assisting me in this interview with communication. If at any point you do not understand me I will use my AAC device or ask David to re-voice what I said."*	
		2.3	Confirmations	
	D		*"Before we start the actual interview we need to go through a couple of things. These may seem tedious and unnecessary, however they are requirements of the university."*	
		2.4	Establishing reliable Yes and No responses	
	D		*"Firstly we need to work out a reliable Yes/No response that you can do without assistance. How do you want to do this?"*	
		2.5	Video-recording	
	D		*"Ok, now we have established how you can communicate Yes and No, I need to ask again, as I asked before the video camera was turned on, are you happy for me to video record this interview?"* (Confirming ability to give consent)	
	D	2.6	*"I am going to ask you five questions that will require Yes or No answers. These next five questions are to make sure you understand and want to take part in this interview. Please answer them to the best of your ability with a simple Yes or No."*	
	D	2.6.1	*"OK, the first question is. Are you being forced to participate or are you being pressured to participate in this interview?"*	
	D	2.6.2	*"Can you say that you want to stop being interviewed at any time?"*	
	D	2.6.3	*"Could you be interviewed over several sessions?"*	
	D	2.6.4	*"Will your real name appear in the final thesis or any publication of this research?"*	
	D	2.6.5	*Can anyone other than me, my assistant and supervisors access your answers?*	
	D		*"Great, you answer correctly in these questions. But please remember when we get into the interview questions there are no right or wrong answers, you can answer them how you*	



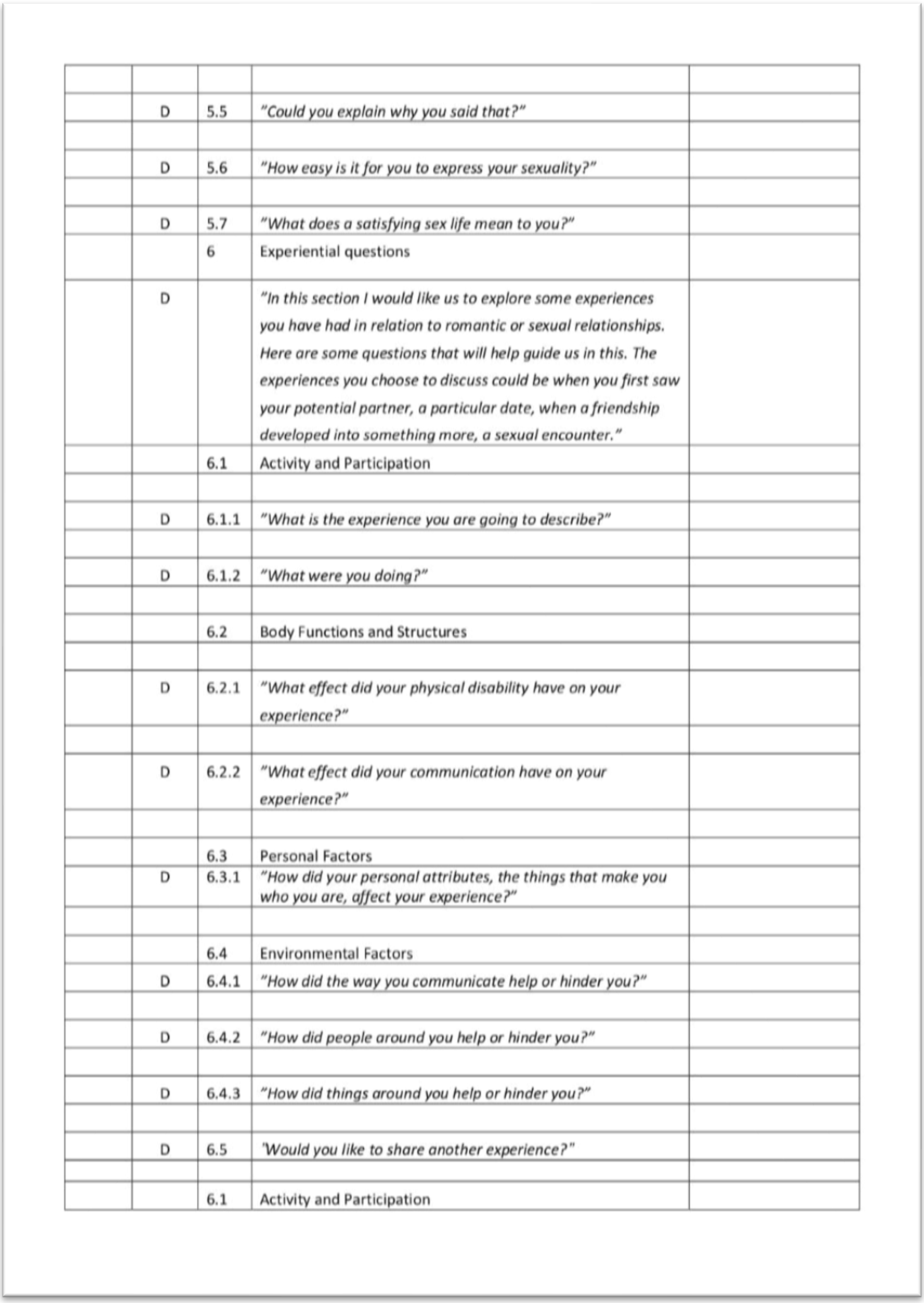
			feel is right for you."	
			OR	
	D		*"It seems that you have trouble with understanding the Participant Information Sheet about this project. Unfortunately, we cannot continue with the interview at this point, so, would you like to read the information sheet again. I can go through it with you, and try these questions again?"*	
			(It would be unlikely that I would need to use the second option, I would hopefully pick up their ability before the commencement of the interview.)	
		2.7	*Information sheet*	
	D	2.7.1	*"From the answers you have just given I can tell that you have read the Participant Information Sheet. Do you have any questions about it?"*	
	D	2.7.2	*"Do you give consent to participate in this interview?"*	
		2.7.3	The role of the communication assistant will be confirmed (if one is present).	
	D		*"As you are using a communication assistant in the interview, I need to stress that I am really interested in what you want to say, so I ask both our assistants to ensure that they only revoice what we are saying. It is OK if you ask them to explain something further, but when this happens I will check with you that they have relayed what you intended."*	
			Proposed Guiding Questions	
	D		*"Now we are ready to begin the actual interview. There are four sections of the interview. The first set of questions is concerned with your personal background. The next is about the kind of social interactions you have. This is followed by a look at your friendships and relationships, and the last set explores some of your experiences in more detail.* *I will remind you again that you may skip on any questions that you don't wish to answer and we can have a break whenever we feel the need."*	



		3	Background	
	D		*"OK, let's start. In this section we discuss a bit about where you live, your interests, education, employment and your disability. We also touch on the way you communicate."*	
	D	3.1	*"Describe your home."*	
	D	3.1.1	*"How many people do you live with?"*	
	D	3.1.2	*"What kind of accommodation?"*	
	D	3.1.3	*"Do you feel that you are free to live as you like?"*	
	D	3.2	*"Describe the town or city you live in."*	
	D	3.3	*"What do you do with your time?"*	
	D	3.3.1	*"Would you like to tell me about some of your hobbies and Interests?"*	
	D	3.3.2	*"Would you like to tell me about your friends?"*	
	D	3.3.3	*"Would you like to tell me about your work?"*	
	D	3.4	*"What is your primary disability?"*	
	D	3.5	*"What is your primary way of communicating?"*	
	D	3.6	*"What are some of the other kinds of ways you communicate?"*	
	D	3.7	*"When do you use these ways of communication?"*	
	D		*"We are at the end of the first section. Well done. Would you like to have a break or would you prefer to continue?"*	
		4	Social interaction	
	D		*"These next questions are around the kind of social interactions you have experienced."*	
	D	4.1	*"Tell me about your social life."*	



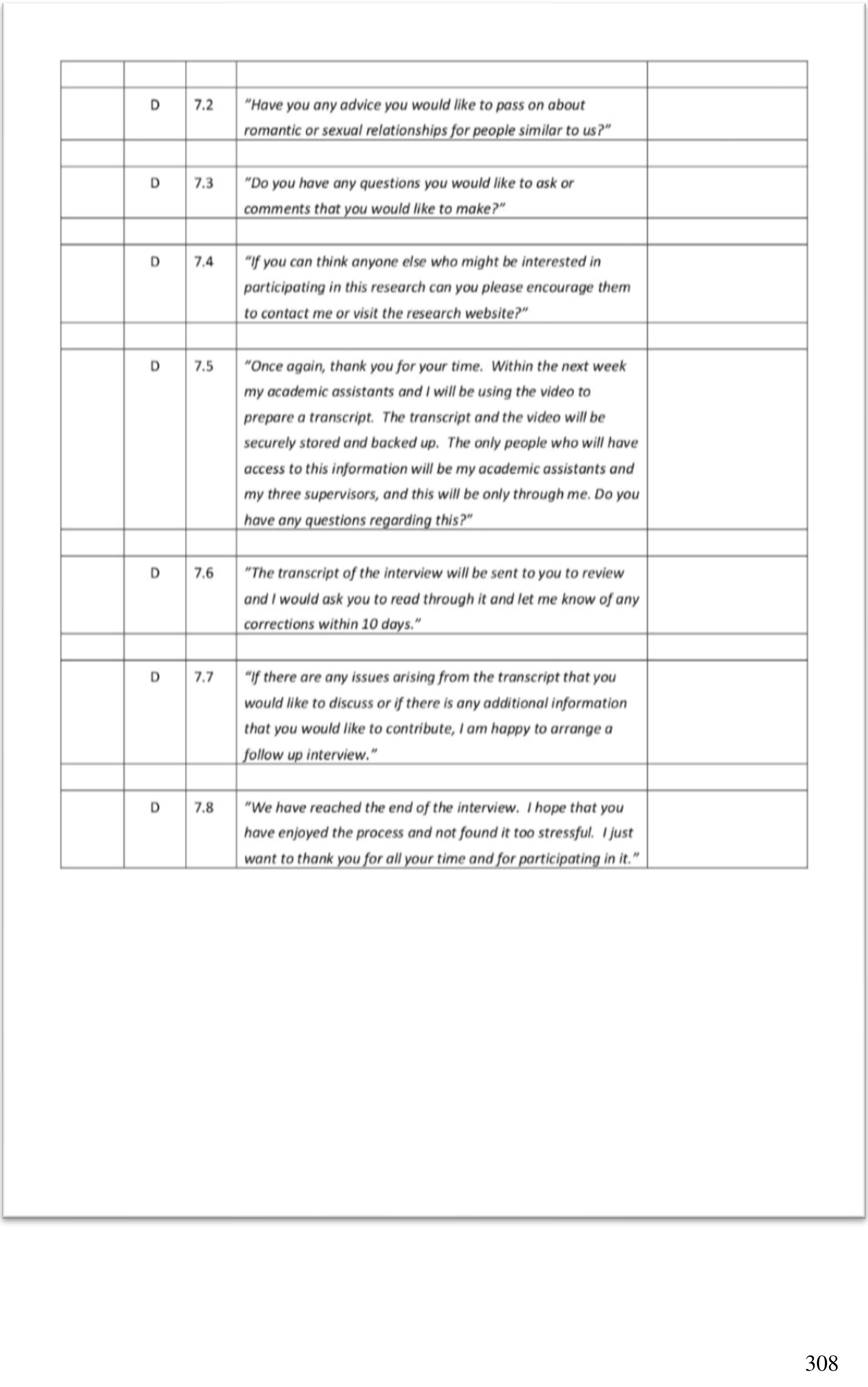
	D	4.1.1	*"What are some of the social events and activities you attend?"*	
	D	4.1.2	*"How often do you go out to them?"*	
	D	4.1.3	*"Who do you go with?"*	
	D	4.1.4	*"Who do you communicate with most in these events?"*	
	D	4.2	*"What makes it easy for you communicating when you go out?"*	
	D	4.3	*"What makes communicating difficult for you at social events?"*	
	D	4.4	*"What makes it difficult for you to meet new people in social events?"*	
	D	4.5	*"What makes it easier for you to meet new people in social events?"*	
	D		*"We are at the end of the second section. Well done. Would you like to have a break or would you prefer to continue?"*	
		5	Relationships and Friendship	
	D		*"The questions in this section explore the friendships and intimate relationships. Remember, you do not have to answer any question that you don't want to."*	
	D	5.1	*"In your teens years, what kind of close intimate relationships did you have?*	
	D	5.2	*"And now in your adult years, what kind of intimate relationships have you had?"*	
	D		*"Can you separate the two? First teen years and then adult life?"*	
	D	5.3	*"What kind of people do you prefer in intimate relationships?"*	
	D	5.4	*"Are you satisfied with the intimate relationships you have had?"*	



	D	5.5	*"Could you explain why you said that?"*	
	D	5.6	*"How easy is it for you to express your sexuality?"*	
	D	5.7	*"What does a satisfying sex life mean to you?"*	
		6	Experiential questions	
	D		*"In this section I would like us to explore some experiences you have had in relation to romantic or sexual relationships. Here are some questions that will help guide us in this. The experiences you choose to discuss could be when you first saw your potential partner, a particular date, when a friendship developed into something more, a sexual encounter."*	
		6.1	Activity and Participation	
	D	6.1.1	*"What is the experience you are going to describe?"*	
	D	6.1.2	*"What were you doing?"*	
		6.2	Body Functions and Structures	
	D	6.2.1	*"What effect did your physical disability have on your experience?"*	
	D	6.2.2	*"What effect did your communication have on your experience?"*	
		6.3	Personal Factors	
	D	6.3.1	*"How did your personal attributes, the things that make you who you are, affect your experience?"*	
		6.4	Environmental Factors	
	D	6.4.1	*"How did the way you communicate help or hinder you?"*	
	D	6.4.2	*"How did people around you help or hinder you?"*	
	D	6.4.3	*"How did things around you help or hinder you?"*	
	D	6.5	*'Would you like to share another experience?"*	
		6.1	Activity and Participation	

	D	6.1.1	*"What is the experience you are going to describe?"*	
	D	6.1.2	*"What were you doing?"*	
		6.2	Body Functions and Structures	
	D	6.2.1	*"What effect did your physical disability have on your experience?"*	
	D	6.2.2	*"What effect did your communication have on your experience?"*	
		6.3	Personal Factors	
	D	6.3.1	*"How did your personal attributes, the things that make you who you are, affect your experience?"*	
		6.4	Environmental Factors	
	D	6.4.1	*"How did the way you communicate help or hinder you?"*	
	D	6.4.2	*"How did people around you help or hinder you?"*	
	D	6.4.3	*"How did things around you help or hinder you?"*	
	D	6.5	*'Would you like to share another experience?"*	
		6.1	Activity and Participation	
	D	6.1.1	*"What is the experience you are going to describe?"*	
	D	6.1.2	*"What were you doing?"*	
		6.2	Body Functions and Structures	
	D	6.2.1	*"What effect did your physical disability have on your experience?"*	
	D	6.2.2	*"What effect did your communication have on your experience?"*	
		6.3	Personal Factors	

	D	6.3.1	*"How did your personal attributes, the things that make you who you are, affect your experience?"*	
		6.4	Environmental Factors	
	D	6.4.1	*"How did the way you communicate help or hinder you?"*	
	D	6.4.2	*"How did people around you help or hinder you?"*	
	D	6.4.3	*"How did things around you help or hinder you?"*	
	D	6.5	*'Would you like to share another experience?"*	
		6.1	Activity and Participation	
	D	6.1.1	*"What is the experience you are going to describe?"*	
	D	6.1.2	*"What were you doing?"*	
		6.2	Body Functions and Structures	
	D	6.2.1	*"What effect did your physical disability have on your experience?"*	
	D	6.2.2	*"What effect did your communication have on your experience?"*	
		6.3	Personal Factors	
	D	6.3.1	*"How did your personal attributes, the things that make you who you are, affect your experience?"*	
		6.4	Environmental Factors	
	D	6.4.1	*"How did the way you communicate help or hinder you?"*	
	D	6.4.2	*"How did people around you help or hinder you?"*	
	D	6.4.3	*"How did things around you help or hinder you?"*	
	D	6.5	*'Would you like to share another experience?"*	
		7	Closing	
	D	7.1	*"Great stuff. We are at the end of the interview. However, I would like to give you a chance to add anything further."*	



	D	7.2	*"Have you any advice you would like to pass on about romantic or sexual relationships for people similar to us?"*	
	D	7.3	*"Do you have any questions you would like to ask or comments that you would like to make?"*	
	D	7.4	*"If you can think anyone else who might be interested in participating in this research can you please encourage them to contact me or visit the research website?"*	
	D	7.5	*"Once again, thank you for your time. Within the next week my academic assistants and I will be using the video to prepare a transcript. The transcript and the video will be securely stored and backed up. The only people who will have access to this information will be my academic assistants and my three supervisors, and this will be only through me. Do you have any questions regarding this?"*	
	D	7.6	*"The transcript of the interview will be sent to you to review and I would ask you to read through it and let me know of any corrections within 10 days."*	
	D	7.7	*"If there are any issues arising from the transcript that you would like to discuss or if there is any additional information that you would like to contribute, I am happy to arrange a follow up interview."*	
	D	7.8	*"We have reached the end of the interview. I hope that you have enjoyed the process and not found it too stressful. I just want to thank you for all your time and for participating in it."*	