



Autism, sociality and friendship: a qualitative enquiry

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Autism, sociality and friendship: a qualitative enquiry

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ABSTRACT

In my thesis, I report on my qualitative enquiry into the meaning of sociality and friendship from the perspective of persons with autism. I sought to make a contribution to knowledge by describing: 1) the meaning that persons with autism attach to sociality and friendship; 2) the barriers that persons with autism encountered in experiencing sociality and friendship; and 3) how persons with autism see these barriers being overcome. Data was gathered from three primary data sources: video blogs, online interviews, and autobiographical accounts published in books. The narratives I reviewed had been posted or written by persons with autism and were subjected to thematic analysis. The enquiry methodology reflected my commitment to emancipatory disability research and my theoretical position of possibilities for an enabling narrative of sociality and friendship for persons with autism.

My analysis of the data evidenced that my sources desired to socialise, make friends, and maintain friendships. Despite their successes in making friends and maintaining friendships, the sources distrusted their sociality that I labelled autistic sociality. The sources regarded predominant neurotype (PNT) sociality as the only trusted pathway to making friends and maintaining friendships. The sources positioned their sociality as a distinct pathway that they described as lacking PNT social skills and personal qualities that didn't enable friends to be made and friendships to be maintained. The PNT meaning of sociality had been internalised by the sources as the correct, obtainable, and only way of being that resulted in their disadvantaged outcome.

For me, the task of overcoming social barriers was regarded by the sources as being their responsibility alone, and could only be achieved by developing PNT social skills and personal qualities. Sources didn't expect the PNT to gain an understanding of their sociality. I argue that this binary of autistic and PNT sociality resulted from encountering the disabling social barriers of normalcy and ableism. I also argue that overcoming these social barriers requires broader constructions of sociality and friendship that include the meaning described by persons with autism. An enabling narrative of sociality and friendship for persons with autism is, therefore, required that deconstructs the binary of autistic and PNT sociality for persons with autism and argues for a range of sociality and friendship possibilities across being human. There is I conclude **one sociality** that enables friends to be made and friendships to be maintained by both persons with autism and the PNT.

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1 Chapter One: Introduction

1.1 The origins of my area of interest

My son has the label of Asperger Syndrome (AS) and my relationship with him is the origin of my interest in researching sociality and friendship. Now seventeen years of age, my son was diagnosed or labelled with autism at age three years. At age six years this label was clarified as AS. In my role as his mother, I have always supported my son in whatever he aspired to experience. Supporting my son has led to, and facilitated my pursuit of knowledge of autism.

I have observed my son socialising and engaging in friendships with persons both with autism and without, or persons of the predominant neurotype (PNT). However, my son at his own admission has had fewer friends in comparison to his PNT peers and has found it more difficult to make friends and maintain friendships. Although it hasn't always been possible for my son, socialising, making friends, and maintaining friendships has, for me, been the key to his happiness and academic success at school. However, my son has told me on many occasions that he is unhappy and lonely at school as he hasn't had friends, or that his PNT peers are no longer friends with him. From my perspective, my son has been socially isolated at school to a greater extent than his PNT peers.

My son's lived experience presents me with a puzzle or conundrum, i.e., despite his sociality, the positive experience of friendship that he so desires and enjoys is difficult for him to achieve. I suggest that the reason he hasn't at times had friends and has often failed to maintain friendships, is due to a lack of recognition, acceptance and understanding of his sociality by his PNT peers. My son's sociality is, for me, misunderstood by the PNT as equating to not desiring or enjoying friendship. I believe my son experiences a binary of autistic and PNT sociality, i.e., the sociality of his PNT peers enables friends to be made and friendships to be maintained whilst his autistic sociality fails to do so. From my perspective, for my son to make friends and maintain friendships requires him to overcome these disabling social barriers that position his

sociality as inferior, lesser, and other and to describe the PNT meaning of this phenomenon.

My research interest is, therefore, the meaning of sociality and friendship for persons with autism. In section 1.4 of this chapter, I will return to my focus of enquiry. My next two sections justify my choice of terms and data sources that aligns with my theoretical position and supports my researcher positionality. My theoretical position that I summarise in section 2.6, is for my research to present possibilities for an enabling narrative of sociality and friendship for persons with autism and my researcher positionality that I examine in detail in Chapter Three, is a social oppression theory of disability.

1.2 Choice of terms

I used the terms 'person with autism' and 'person with AS' for individuals who identify with or who have been given these labels. I chose 'person with disabilities' to describe people who identify with a label synonymous with a medical definition of impairment. I selected the term 'autistic sociality' to describe how persons with autism relate to and interact with other persons. I adopted the term 'PNT' for those persons who don't have the label of autism or AS, who are seen as neurologically typical, and that represent the majority of the population. For the persons who provided the data for my study, I chose the term 'sources'. The rationale for my choice of terms is presented below¹.

My adoption of the terms 'person with autism' and 'person with AS', recognised the person before any label that they may identify with or have been given. These are examples of person-first language (PFL) in autism. Using PFL (Brown, 2010) demonstrated that I don't regard a label such as autism as the defining characteristic of a person. Authors who have researched the lived experience of persons with autism or AS have also used PFL (Davidson, 2008a and 2008b; Brownlow, 2010; Ochs and Solomon, 2010; Smith, 2011; Hodge, 2012; Calder, Hill, and Pellicano, 2013; O'Dell et. al., 2016). Similarly, I chose to

¹ I justify my choice of the term sources in section 1.3 as an integral part of the discussion as to how I selected my data sources.

use the term 'person with disabilities' that reflected the PFL used by some authors when researching disability (Iacano, 2006; Johnson, 2009; Williams, 2011; Rimmerman, 2013).

I acknowledge that there is a debate in the academic community regarding the choice of terms. Some persons with autism prefer identify first language (IFL) such as 'autistic' and 'aspie' (Sinclair, 1999; Ladau, 2014; Kenny et. al., 2015; Chown, 2017). However, my choice of PFL supports my researcher positionality, a social oppression theory of disability. The only exception I made to PFL in my choice of terms was 'autistic sociality'. I chose this term to: a) reflect the term used in the literature when researching persons with autism (Bagatell, 2010; Ochs and Solomon, 2010; Milton, 2014; Bertilsdotter Rosqvist, Brownlow, and O'Dell, 2015); and b) reflect my link to this emerging field of enquiry, as used by authors who have published such research.

The term 'PNT' was chosen, as I didn't want to infer a preference for a particular neurological state, only that there are more persons without autism than with this label (Chown, 2012). The World Health Organisation (WHO), the directing and co-ordinating authority on international health, cited a global autism prevalence rate that includes AS, of 62 in 10,000 persons or 1 person in 160 (WHO, 2016). Based on the UK population of 64,596,800 (Office for National Statistics, 2016), this ratio equates to approximately 403,730 persons with autism, including AS, or 0.6% of the UK population. These statistics illustrate that the majority of the UK population, 95.4%, doesn't have autism. The term PNT, therefore, merely makes the point, for me, that there are more persons without autism in our society, whilst implying a range of equally valid neurotypes (Chown, 2012). In addition, other authors who have researched the lived experience of persons with autism or AS, from the social model perspective that I support, have used the term 'PNT' (Beardon, 2008a; Hodge, 2012; Chown, 2012).

As an alternative to 'PNT', I considered using the term 'non-disabled persons' but many persons with autism or AS don't consider themselves disabled (Schafer, 2009; Downing, 2014; Rutherford, Butcher, and Hepburn, 2016).

'Non-disabled' also implies, from my perspective, persons with no physical or cognitive impairments. Using this term would have excluded a person with a physical or different cognitive impairment other than autism or AS from the PNT population. Finally, the term 'non-disabled person' doesn't support my use of PFL. I also considered the term 'neurotypical'. However, I feel this term infers that 'neurotypical' persons are 'normal' and has connotations of a person with autism being lesser or other (Beardon, 2008a; Chown, 2012). In summary, I chose the term 'PNT' to describe persons without autism and to differentiate them from persons with autism in my thesis.

I recognise that other terms may be thought to be more appropriate by other researchers and authors and that my choice is open to challenge and debate. However, my choice reflected my researcher positionality, theoretical position, and aligned me with other academics researching disability, in particular, autism, sociality, and friendship (Beardon, 2008b; Bagatell, 2010; Brownlow, 2010; Chown, 2014). Having provided the rationale for my use of key terms in my thesis, I now provide a brief discussion of how I selected my data sources.

1.3 Data sources

In Chapter Three, I present the rationale for my choice of data sources that I summarise here. Briefly, my choice needed to support my research positionality and align with my theoretical position. As I examine later in my thesis, I believe this could only be achieved by researching the meaning of sociality and friendship described by persons with autism from their perspective. I chose, therefore, to use data sources that were the narratives of persons with autism of their lived experience of sociality and friendship.

For my research, I selected three data sources: YouTube video blogs, Healthtalk website interviews and published autobiographical accounts in a selection of books. All video blogs, online interviews, or books had been posted or written by persons with autism. Established in 2005:

YouTube is a video hosting service that features user generated content or in other words, it is a site where registered users (i.e.,

anyone who creates an account with YouTube) can upload files containing video and unregistered users (i.e., anyone with a connection to the Internet) can view the videos (Chenail, 2011, p229).

YouTube has been used as a data source by numerous authors undertaking qualitative research (Chenail, 2011; Konijn, Veldhuis, and Plaisier, 2013), including in the field of autism (Brownlow, O'Dell, and Bertilsdotter Rosqvist, 2013).

Healthtalk, created in 2001 by the Health Experience Research Group (HERG) at Oxford University “provides a balanced, evidence-based reflection of what is important to patients, presented through video and audio interview clips as well as written material” (Kidd and Ziebland, 2016, p274). Data is presented as web pages that provide information on health issues and illnesses from over three thousand interviews. Healthtalk data has been used by academics including those researching autism or AS (Ryan and Salisbury, 2012; Ryan, 2013).

Finally, I chose autobiographical accounts in books written by persons with autism. Listening to accounts of a person's lived experience of a phenomenon is an established data source (Mathias and Smith, 2016). These authors write that autobiographical accounts provide a breadth and depth of knowledge of a person's lived experience and present researchers with a unique and unparalleled research opportunity. Van Manen (2016, p72) described the genre as, “rich ore of lived-experience descriptions”. Autobiographical accounts have previously been used as a data source in researching the lived experience of persons with autism (Barrett, 2006; Chamak et. al., 2008; Rose, 2008; Davidson and Smith, 2009; Ochs and Solomon, 2010; Bertilsdotter Rosqvist, Brownlow, and O'Dell, 2013).

The persons who posted their video blogs on YouTube, gave their permission to have their interview posted on Healthtalk, or published their autobiography, I was unable to co-construct data with. Therefore, I didn't feel it was appropriate to refer to them as 'participants' and decided to refer to persons who had contributed to my research as 'sources'. This choice of term was based on the

definition of 'source' as an entity "from which something comes into being or is derived or obtained" (The Free Dictionary, 2016, no page number).

From my perspective, the sources in my study identified with the label of autism or AS². From viewing and reading the video blogs, interviews, and autobiographical accounts, the sources could be regarded as high functioning (HF), i.e., with an Intelligence Quotient of greater than seventy (Pasco, 2011; Attwood, 2013). These authors stated there is much debate as to whether there is a difference between HFA and AS. The main diagnostic difference between HFA and AS is that there are no significant developmental delays in developing cognitive language with AS whilst there are such delays in HFA (Attwood, 2013). However, this author concluded that the similarities between HFA and AS outweighed the differences and that both terms could be used interchangeably. In acknowledging this debate, when referring to the sources in my thesis, I chose to use the term 'person with autism' on the basis that AS and HFA are variants of this diagnostic label. To reflect the label that each source identifies with, autism or AS was recorded in their profile as appropriate in Appendix One. All further references to 'persons with AS' in my thesis is either to my son's diagnosis or reflects the terms used by the authors that I have cited and referenced.

I acknowledge that my selection of data sources is open to challenge and debate. Numerous research projects for persons with autism have been conducted using other data sources such as interviews (Howard, Cohn and Orsmond, 2006; Healy, Msetfi, and Gallagher, 2013; Martin, 2015), observations (Ochs et. al., 2001; McMahon, Vismara, and Solomon, 2013; Kasari et. al., 2016), and questionnaires (Heiman, 2000; Locke et. al, 2010; Martin, 2015). My choice of data sources also aligned with that of other academics researching disability, and in particular sociality and friendship in relation to autism (Davidson and Smith, 2009; Brownlow, O'Dell, and

²For the sources the label of autism or AS may have originated from a medical or self-diagnosis. As I wasn't able to co-construct data with the sources, I was unable to determine the process by which each source had identified with their label. Regardless of the method of diagnosis, I regarded the label the source identified with as reliable.

Bertilsson Rosqvist, 2013; Ryan, 2013). Having sought to justify my choice of terms and data sources, I now critique the gap in knowledge that I wished my research to inform.

1.4 The gap in knowledge

The origin of my focus of enquiry is the sociality and friendship experiences of my son who has the label of AS. Observing my son socialise and listening to him articulate his desire for and enjoyment of friendship, has led me to question why making friends and maintaining friendships is difficult for him. I questioned whether concepts of sociality and friendship are being imposed upon him by the PNT that have little meaning for him and are disabling. To identify whether this barrier had been addressed within the published literature, the Sheffield Hallam University (SHU) educational databases were searched for the terms of AS or autism, together with sociality or friendship. The aim was to identify the dominant discourse as regards sociality and friendship for persons with autism, and any disabling concepts associated with them.

Researching the friendship and sociality of persons with autism has received limited attention from the academic community (Neysa, Carter, and Stephenson, 2014; Bertilsson Rosqvist, Brownlow, and O'Dell, 2015). Reports of research of the lived experience of persons with autism described friends and friendships with persons with autism and of the PNT (Jones and Meldal, 2001; Bauminger and Shulman, 2003; Daniel and Billingsley, 2010; Solomon, Bauminger, and Rogers, 2011; Rowley et. al., 2012; Kuo et. al., 2013; Neysa, Carter, and Stephenson, 2014). However, in comparison to the PNT persons with autism were said to have fewer friends, and found it more difficult to make friends and maintain friendships (Bauminger and Shulman, 2003; Kasari et. al., 2011; Rowley et. al., 2012; Neysa, Carter, and Stephenson, 2014). Friends and friendships were found also to be of poorer quality for persons with autism, in comparison to their PNT peers (Whitehouse et. al., 2009; Locke, et. al., 2010; Calder, Hill, and Pellicano, 2013; Bossaert et. al., 2015).

These findings supported the diagnostic criteria for autism and AS (APA, 2013b). According to the American Psychiatric Association (APA), the world's leading psychiatric organisation, persons with autism have difficulty building friendships appropriate to their age (APA, 2013a). The dominant discourse in the published literature claimed this difficulty in building friendships was due to a lack of social skills of persons with autism (Bauminger, Solomon, and Rogers, 2010; Daniel and Billingsley, 2010; Locke et. al., 2010; Solomon, Bauminger, and Rogers, 2011; Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014³). Orsmond, Wyngaarden-Krauss, and Seltzer (2004) concluded that the more severe the impairments of persons with autism the less likely they were to make friends. These findings also supported the conundrum that I have observed in my son, i.e., despite his sociality the positive experience of friendship that he so desires and enjoys is difficult for him to achieve. I argue that a binary of autistic and PNT sociality exists in that PNT sociality allows friends to be made and friendships to be maintained. In comparison, for me, autistic sociality is positioned in the literature as lesser and other and encounters disabling social barriers that prevent persons with autism from doing so.

My analysis of the literature cited above has evidenced a gap in autism research, i.e., the meaning of the phenomena of sociality and friendship for persons with autism that described their lived experience from their perspective. To address this gap in knowledge I formulated research questions and these are presented in the following section.

1.5 Research questions

My research aimed to address this gap in knowledge and contribute to resolving the conundrum that I have observed in my son and I have found support for in the literature, i.e., that despite their sociality, the positive experience of

³ Many authors in the published literature claimed that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills. Throughout my thesis I refer to this claim in the literature by citing the two most recent publications as examples of authors (Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014) whom have reached this conclusion.

friendship that persons with autism desire and enjoy is difficult for them to achieve⁴. To do so, my research aimed to answer the following research questions:

1. What meaning do persons with autism describe of the phenomena of sociality and friendship?
2. What barriers do persons with autism encounter in experiencing sociality and friendship?
3. How do persons with autism see these barriers being overcome?

To answer these questions, I undertook a qualitative enquiry that described the lived experience of sociality and friendship of persons with autism from their perspective. The rationale for this approach was informed by my theoretical position and researcher poisionality. In providing answers to my questions, I sought to make a contribution to knowledge that informed my own and professional practice. I now conclude this chapter by presenting the structure of my thesis.

1.6 Thesis structure

My thesis is structured in five chapters, that allows me to present my research and findings effectively and coherently in support of the claim to knowledge that I'm making:

- **Chapter One Introduction** - establishes the context for my research, introduces my research interest, summarises its significance, and presents my research questions.
- **Chapter Two Literature review** – presents a synthesis of the published literature relevant to understanding the research that has been undertaken on autism, sociality, and friendship. In doing so, I define my theoretical

⁴ This was the aim of the outcome of my research.

position and use this as a lens to interpret key concepts of relevance to my focus of enquiry. The review includes discussion of disabling concepts and identifies gaps in knowledge.

- **Chapter Three Philosophical and methodological framework** – describes my rationale for the choice of methodology and methods in the context of my theoretical position and researcher positionality. This chapter also critiques ethical issues, summarises the sources used, and describes the process of data collection and analysis undertaken.
- **Chapter Four Findings** – presents the findings of my research in terms of the themes of sociality and friendship identified for persons with autism in my study.
- **Chapter Five Discussion and implications for professional practice** - This chapter critically evaluates the significance of the findings in the context of my literature review. In my discussion, I then examine my research in terms of its limitations, further research opportunities, reflect on my researcher positionality, and opportunities to inform professional practice.
- **Chapter Six Summary and conclusions** - summarises the research process, its' outcomes, and the implications for the meaning of sociality and friendship for persons with autism.

Having introduced the focus of my research in Chapter One, I present my literature review in Chapter Two.

2 Chapter Two: Literature review

2.1 Introduction

In Chapter One, I established the context for my research, introduced my focus of enquiry as the meaning of sociality and friendship for persons with autism from their perspective, and presented my research questions. In this chapter, I have reviewed the published literature relevant to understanding the research that has been undertaken on autism, sociality, and friendship, and identified any disabling concepts and gaps in knowledge. In doing so, the aim of my literature review was to: 1) define my theoretical position; 2) interpret key concepts of relevance to my research using my theoretical perspective; and 3) to learn from other research that adopts my position.

I commence my literature review by defining the theoretical framework for my research. As stated in the literature, there are different understandings of autism (Aylott, 2001; Heilker and Yergeau, 2011; O'Dell, et. al., 2016; Richards, 2016). Milton (2014, p794) writes, "The field of autism studies is a highly disputed territory within which competing contradictory discourses abound". I examine these differing discourses or understandings of autism that I present in sections 2.3 to 2.5. At the end of each sub-section I summarise my position regarding the understanding of autism that I have examined. In section 2.6, I present an overview of my theoretical position that I use to interpret key concepts of relevance to my focus of enquiry in sections 2.7 to 2.12.

I begin by reviewing the literature that I introduced in section 1.4, to identify whether the conundrum that I have observed in my son has been found in researching persons with autism, i.e., despite their sociality, the positive experience of friendship that is so desired and enjoyed is difficult for them to achieve. This will enable me to present my rationale for refuting or supporting the different understandings of autism that I subsequently explore.

2.2 The conundrum of sociality, making friends, and maintaining friendships

As I described in Chapter One, my son's lived experience of sociality and friendship presents, for me, a conundrum, or, a puzzle, i.e., despite his sociality, the positive experience of friendship that he so desires and enjoys is difficult for him to achieve. My review of the literature found that other persons with autism also described this meaning.

The first autobiographical accounts of persons with autism (Eastham, Pate, and Grice, 1985; Miedzianik, 1986; Grandin and Scariano, 1986) were published in the 1980s. By the 1990s, many accounts had emerged by persons with autism that described their lived experience from their perspective (Baggs, 2013). With the creation of the World Wide Web in 1989 (World Wide Web Foundation, 2015), social networking such as Facebook in 2004 (Black, Moyer, and Goldberg, 2016), and YouTube in 2005 (Snelson, 2011) persons with autism now had a platform to describe and potentially communicate their lived experience to a global audience⁵.

Sinclair (2010, no page number) described the difficulties he had experienced in socialising and making friends and maintaining friendship and stated, "Most autistic adults have experienced a lifetime of difficulties and disappointments with interpersonal connections". An author with autism said, "many of the autistic teens I have met are desperate for friendships" (Wyatt, 2011, p1). Other authors of autobiographical accounts (Bliss, 2008; Hughes, 2008; Pandya, 2008; Worton, 2008) stated that despite the difficulties they had encountered from the PNT, they had made friends and maintained friendships. Tobin, Drager, and Richardson (2014) undertook a systematic review of the literature of social participation of adults with autism. These authors found that many of the adults with autism desired social contacts but had few relationships with other people. Other authors concluded from their research of adolescents with autism that in comparison to their PNT peers "Impairments in communication

⁵ The World Wide Web has provided a platform for anyone who wishes and is able to, regardless of any labels they may identify with, to describe and communicate their lived experience to a global audience.

and social reciprocity lead to greater difficulties in socialisation and development of meaningful social relationships” (Stokes, Newton and Kaur, 2007, p1978).

Cage, Bird, and Pellicano (2016) researched both the perspective of adolescents with autism and of their teachers. Both groups thought the adolescents with autism found friendship difficult as they struggled to understand social rules. Other research has found that “Both parents and teachers agreed that one of the predominant challenges for the students in developing friendships was the difficulties they had in understanding social conventions” (O’Hagan and Hebron, 2017, p322). These authors also concluded that the children with autism in their study, whilst wanting to join in, make friends, and maintain friendships, as a result of their unconventional social approaches, had been excluded by their PNT peers. Ochs et. al., (2001) observed behaviours of children with autism who were rejected and scorned by their PNT classmates but still pursued friends and friendship. Other research concluded that despite the difficulties persons with autism encountered from the PNT, they had made friends and maintained friendships (Jones and Meldal, 2001; Brownlow, Bertilsdotter Rosqvist, and O’Dell 2015).

My review of the literature found that other persons with autism had experienced the same conundrum that I have observed in my son, i.e., that despite their sociality, the positive experience of friendship that they so desire and enjoy is difficult for them to achieve. I suggest my son’s sociality, and that of other persons with autism described in the literature may, therefore, be misunderstood by the PNT as equating to not desiring or enjoying friendship resulting from the binary of autistic and PNT sociality. From my perspective, PNT sociality enables friends and friendships to be made whilst autistic sociality fails to do so, and has resulted in the dominant discourse that persons with autism find it difficult to make friends and maintain friendship due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). For persons with autism including my son to make friends and maintain friendships requires them, for me, to overcome these disabling social barriers

that positions their autistic sociality and friendships as inferior, lesser, and other and to describe the PNT meaning of these phenomena.

In defining my theoretical position, my aim is for the outcome of my research to contribute to resolving this conundrum. To do so, my theoretical position must present possibilities for an enabling narrative of sociality and friendship for persons with autism that: 1) deconstructs the binary of autistic and PNT sociality, and, therefore, advances a challenge to this dominant discourse on sociality and friendship and; 2) argues for a range of sociality and friendship possibilities across being human.

To define my theoretical position, I begin by examining different discourses of autism. In section 2.3, I explore discourses that I argue I must reject as they don't support the aim for the outcome of my research. In sections 2.4 and 2.5, I then examine understandings of autism that I argue support my theoretical position that I summarise in section 2.6. I begin then by examining the dominant understanding of autism that is the medical model of disability ideology (O'Dell, et. al., 2016) that I must reject.

2.3 The medical model of disability ideology

2.3.1 The origins of autism

The label 'autistic' has its origins in work completed in the 20th century by the psychiatrist Bleuler (Frith, 2003; Chown, 2017). Bleuler in his work on schizophrenia had used 'autistic' to mean a narrowing of relationships to exclude everything and everyone in individuals outside of the person's own self. He derived the term or label 'autistic' from the Greek word autos meaning self (Baron-Cohen, 2005).

In 1948, Kanner, an American child psychiatrist, presented autism as a diagnostic category (Nadesan, 2005). Kanner published his findings of a study of eleven children that cited "inborn autistic disturbances of affective contact" (Kanner, 1943, p250). Kanner introduced the salient features of classic autism,

based on his understanding of autism as a deficit model of disability that he described as autistic aloneness, desire for sameness, and islets of ability.

In 1944, Asperger published *Autistic psychopathology* (Jones and Meldal, 2001). Asperger's dissertation critiqued the development and behaviour of several young boys of average intelligence and language, but who also exhibited autistic-like behaviours and marked deficiencies in social and communication skills (Jones and Meldal, 2001). Asperger, like Kanner, claimed that a disturbance of contact existed at some deep level within the children that he observed.

From my perspective, Kanner and Asperger both position persons with autism as being deficient and impaired in comparison to the PNT. In doing so, they laid the foundations of the concept of a binary of autistic and PNT sociality that has resulted in this dominant discourse on sociality and friendship of persons with autism that I have identified. In the decades that followed, autism and disability research in general, remained the preserve of the medical community (Vehmas, Kristiansen, and Shakespeare, 2009). Persons with disabilities, including those with autism, were neglected and disempowered in research and positioned as having nothing of worth to say as I now explore (Stone and Priestley, 1996; Milton, 2014).

2.3.2 Researching disability

Researching the lived experience of persons with disabilities has focused on medical aspects of disability in terms of bodies in need of repair (Mallett and Runswick-Cole, 2014). The focus of academics on researching disability has been from the perspective of the PNT as the ideal state⁶ (Mallett and Runswick-Cole, 2014). Historically, disability has been researched in relation to other issues such as euthanasia, abortion, and justice, rather than as a subject in its own right (Vehmas, Kirstiansen, and Shakespeare, 2009). As described by these authors, rarely have the social, cultural, or political factors that result in

⁶ I'm not implying that researching from the PNT as the ideal state may or may not have been a conscious decision by the researcher. Merely, that this is the perspective adopted in the published literature.

people's disablement been taken into account, i.e., the structures, beliefs, customs, and organisation of the society in which persons with disabilities live. The academic community has, therefore, been slow to embrace diversity and persons with disabilities and other minority groups have been marginalised. Research has generally focused on rehabilitation of persons with disabilities at the expense of political and societal factors (Olkin and Pledger, 2003). Taub and Fanflik (2000) identified two key themes in disability research, as defining characteristics and as the basis for membership of minority groups.

In disability research, there has historically been a power imbalance with the PNT researcher cast as the expert, i.e., the researcher controlled what was of interest, how to research, and whom to research with (Nicolaidis, 2012). The result was that persons with disabilities, the researched, including persons with autism, have almost always been alienated from the research process (Oliver, 1992). Historically, it has been the views of parents and professionals, mainly of the PNT, that has been the focus of interest in academic research as to the lived experience of persons with autism (Brewin, Renwick, and Schormans, 2008; Ryan and Salisbury, 2012; Shire et. al., 2015).

It wasn't until the emergence of disability studies in the mid-1980s that the lived experiences of persons with disabilities from their perspective became a focus of enquiry for the academic community (Ferguson and Nusbaum, 2012). The published literature has, therefore, for me, traditionally positioned the experience of the sociality of persons with autism, as inferior and lesser compared to the meaning described by the PNT.

This medical model of disability understanding of autism adopted by the research and medical communities has informed social and cultural practice. I now examine how this deficit understanding of autism has arisen in our PNT society.

2.3.3 Autism as a social construct

Oliver (1992, p101) wrote, “disability is⁷ socially produced” and is a product of how society views ability. The view of our PNT society is that disability is aligned with ‘impairment’, either physical, cognitive, or both. Persons with ‘impairments’, including those with autism, are, therefore, unable to describe the preferred lived experience of persons with ‘ability’. Runswick-Cole (2014, p1118) refers to this as the “autism as a disorder narrative; that is the view that if you have autism, there is ‘something wrong with you”.

Nadesan (2005, p5) stated, “Autism is a disorder of the early twentieth century while the high-functioning variants of autism such as Asperger’s Syndrome (AS), and Pervasive Development Disorder (PDD) are fundamentally disorders of the late twentieth-early twenty-first centuries.” This author claimed that the label of autism couldn’t have existed any earlier, as the diagnostic criteria hadn’t been developed to allow its definition, i.e., firstly, normality had to be defined through social and cultural practice. Then cognitive differences viewed by society as impairments were socially constructed as autism and positioned as a disorder, resulting in the disablement of persons with this label. From the perspective of a PNT society autism was said to be a puzzle that needed to be solved and a “mystery of the mind” (McGuire and Michalko, 2011, p162).

Today, as a result of social and cultural practice, autism is often understood as a medical problem (O’Dell et. al., 2016). The conventional approach is for the predominantly PNT medical profession⁸ to diagnose autism based upon this deficit or medical model of disability (WHO, 2010; APA, 2013b). I now examine current diagnostic criteria in the context of my focus of enquiry that is the sociality and friendship of persons with autism.

⁷ Disability as defined by the social model of disability.

⁸ 2% of students accepted for medical training in the UK declared a disability or a chronic illness. The results of surveys of doctors with disabilities in the UK varied by location but have been recorded as having a prevalence rate as low as 0.002%. In the USA and Canada, a prevalence rate of 2-5% of doctors with disabilities has been reported (Snashall, 2009).

2.3.4 Diagnostic criteria

In the medical model of disability, the critical element is the location of the 'problem' of disability within the individual (Oliver, 2006; Oliver and Barnes, 2010). This model regards disability as arising out of the individual's impairment, with the emphasis on the person to seek an improvement or cure for their disability (Swain, French, and Cameron, 2003; Michalko, 2008; Mallett and Runswick-Cole, 2014).

Today, autism is diagnosed using either the medical model of disability criteria as presented in the Diagnostic and Statistical Manual (DSM) of the APA (APA, 2013b) or the International Classification of Diseases (ICD) of the WHO (WHO, 2010). Initially, autism was only included as a criterion for childhood schizophrenia (Straus, 2013). It wasn't until the publication of the ICD-9 in 1979 and the DSM-III in 1980 that childhood autism was recorded as a distinct classification (Oller and Oller, 2010). The current WHO diagnostic criteria for autism is defined in Chapter V Mental and Behavioural Disorders as follows (2010, C5, F84.0)⁹:

Childhood Autism: A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. In addition to these specific diagnostic features, a range of other nonspecific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.

In 1981, Wing translated into English the work of Asperger and introduced the phrase 'Asperger Syndrome' (AS) (Jordan, 1999). AS was included for the first time in the DSM-IV (APA) in 1994 (Oller and Oller, 2010). A diagnosis of AS may be given to persons who have had no delay with language or their intellectual development, but have difficulties with social communication and

⁹ F84.0 also includes a reference to autistic disorder, infantile autism, and psychosis and Kanner syndrome. F84.1 defines atypical autism.

interaction (Attwood, 2013). Today, AS is formally defined in the WHO-ICD 10 (2010, Ch5, F84.5)¹⁰ as:

Asperger Syndrome: A disorder of uncertain nosological validity, characterised by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.

There is no equivalent diagnostic category for AS in the current APA DSM-5 (APA, 2013b). Version five was republished in 2013, and several changes were made. The diagnostic criteria for autism were reduced to two, combining social communication and social interaction into one criterion, with restricted, repetitive patterns of behaviour the second. Sensory perceptual issues and levels of severity were included in the criteria with AS no longer included as a separate diagnostic category. The APA concluded there was no longer sufficient evidence to differentiate AS from high-functioning autism and, therefore, removed this classification (APA, 2013a). The WHO when they republish ICD in 2018 is anticipated to make similar amendments to their diagnostic criteria for autism and AS. This harmonisation of diagnostic criteria between the APA and the WHO is supported by the psychiatric profession (First, 2009).

Whilst friendship isn't directly referred to in either the APA or WHO diagnostic criteria, the APA criteria do include references to sociality in terms of "persistent deficits in social interaction", "abnormal social approaches", "reduced sharing of interests", and "failure to initiate or respond to social interactions" (APA, 2013b, 299.00, F84.0). The WHO diagnostic criteria refer to "abnormal functioning in reciprocal social interaction" (WHO, 2010, Ch 5, F84.0) that, for me,

¹⁰ F84.5 also includes a reference to autistic psychopathy and schizoid disorder of childhood. Whilst the WHO has issued annual official updates to ICD-10 these haven't changed the criteria for autism or AS.

perpetuates the binary of autistic and PNT sociality and this dominant discourse on sociality and friendship of persons with autism.

Having examined the medical model of disability understanding of autism that predominates in our society, I now summarise my theoretical position in relation to this thinking.

2.3.5 Summary

Researching the lived experience of persons with disabilities has focused on medical aspects of disability in terms of bodies in need of repair (Mallett and Runswick-Cole, 2014). As described by these authors, the focus of academics on researching disability has been from the perspective of the PNT as the ideal state¹¹. From the perspective of many academics and practitioners, and as I have outlined in relation to my perspective, the medical model of disability ideology, therefore, positions persons with autism as deficient and impaired in comparison to the PNT and this understanding of autism has resulted in the binary of autistic and PNT sociality. Furthermore, for me, the medical model of disability understanding of autism has given rise to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014).

Chamak et. al., (2008) compared the personal experience of persons with autism with medical and scientific knowledge and understandings of autism, developed predominantly by PNT professionals. This research found that sensory perceptual issues, information processing, and emotional sensitivity were the key concerns of the participants but weren't mentioned in diagnostic criteria. The perspective of the person with autism, therefore, may be contrary to that of the medical understanding of autism (Smith and Sharp, 2012; Mackenzie and Watts, 2013; Gillespie-Lynch, et. al., 2017). I must, therefore, reject the medical model of disability ideology that from my perspective has

¹¹ I'm not implying that researching from the PNT as the ideal state may or may not have been a conscious decision by the researcher. Merely, that this is the perspective adopted in the published literature.

established and perpetuated the conundrum of socialising but finding it difficult to maintain friendships, and doesn't present possibilities for an enabling narrative of sociality and friendship for persons with autism.

I acknowledge that some persons with autism may disagree with my rejection of the medical model of disability understanding of autism. Richards (2016) writes that some persons with autism don't regard their label as an issue and are proud of it. Other authors have found that the experience of diagnosis was liberating for some teenagers, gave them a sense of control over their life, or a positive identity (Mogensen and Mason, 2015). Persons with autism have also described their positive feelings towards diagnosis (Lewis, 2016). However, in the context of my research, the dominant medical model of disability ideology doesn't present possibilities for an enabling narrative of sociality and friendship for persons with autism and is contrary to my theoretical position that I must reject.

As stated by O'Dell et. al., (2016) there are other understandings of autism that I now examine in sections 2.4 and 2.5. I argue that these understandings align with the aim for the outcome of my research, i.e., to resolving the conundrum that I have observed in my son and I have found support for in the literature, i.e., despite their sociality, the positive experience of friendship that persons with autism so desire and enjoy is difficult for them to achieve. I begin then by exploring the social model of disability.

2.4 The social model of disability

In 1976, the Union of the Physically Impaired Against Segregation (UPIAS) published *Fundamental principles of disability* (UPIAS, 1976). This paper advocated for the first time a separate definition of impairment from disability:

Impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1976, p20).

UPIAS is credited with establishing the principles that led to the development of the social model of disability (Tregaskis, 2002). Introduced in 1983 by Mike Oliver, the social model of disability conceptualises disability as the oppression by our society of persons with impairments (Oliver, 1983). As described by this author, under this model, disability is located within the social environment rather than the individual. The attitudes of individuals in society and the environmental factors that these inform, result in the disablement of persons with impairments, through presenting barriers to their inclusion in everyday life. The social model of disability transfers the responsibility for making accommodations to overcome these barriers from the individual to society.

From my perspective, the aim of research that epitomises the social model of disability is, therefore, to transform the life of an individual by removing barriers to full participation in the community, in leisure, education, and employment. Thus the social model of disability that is considered the ‘big idea’ of the British disability movement challenges the view that impairment is a tragedy for the individual and the family (Peters, 2008).

In their publication, UPIAS (1976, p20) went on to say, “Physical disability is therefore a particular form of social oppression”. The social model of disability was, therefore, originally conceptualised as a means to understanding physical impairments (Tregaskis, 2002). It was the neurodiversity movement that first extended the social model of disability to understanding cognitive differences including autism that I now examine.

2.4.1 The neurodiversity movement

Judy Singer, a sociologist and person with autism, originally coined the term neurodiversity (Singer, 1999). Singer asserted in her work “The ‘neurologically different’ represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability” (1999, p37).

The neurodiversity movement was initially developed online by groups of

persons with autism (Jaarsma and Welin, 2011). Sinclair, an autism-rights movement activist and a principal contributor to the online autism community in the 1990s, has been credited with making a significant contribution to its development (Boundy, 2008). Subsequently, persons with other labels of neurological difference such as dyspraxia, dyslexia, and attention deficit hyperactive disorder have also embraced and contributed to the development of the neurodiversity movement (Jaarsma and Welin, 2011). Runswick-Cole writes:

The neurodiversity movement offers a counter narrative to the 'autism-as-disorder' model outlined above. Neurodiversity is defined as a biopolitical category concerned with promoting the rights of, and preventing discrimination against, people who are neurologically different from the 'neurotypical' (or the non-autistic) population (2014, p1120).

The neurodiversity movement recognises different human neurotypes, of which autism is one example, as a natural variation of the human (Jaarsma and Welin, 2011). This movement that seeks social justice “draws its roots from a social model of disability” (Kreck, 2013, p11) and uses it to make a distinction between the biological nature of autism and the social oppression by our society of persons with a different neurology such as autism (Runswick-Cole, 2014). Authors in the published literature who support the neurodiversity perspective of difference have adopted the social model of disability when researching the lived experience of persons with autism (Hodge, 2012; Chown, 2012; Martin, 2015).

The social model of disability isn't a static concept and has been subject to review and critique by academics (Shakespeare and Watson, 2002; Thomas, 2007 and Owens, 2014). Beardon (2017) in his most recent work has presented a reconsideration of the social model of disability that I now explore.

2.4.2 The disadvantage of persons with autism

In *Autism and asperger syndrome in adults* (Beardon, 2017), Beardon introduced the following principle, “autism + environment = outcome” (Beardon, 2017, p11). The outcome that is whether the person with autism experiences advantage or disadvantage, is the product of how they experience the world and the environment they inhabit. The author goes on to describe that persons with autism, the minority group in society, are at a higher risk of being disadvantaged compared to the PNT, the majority group or their environment. Beardon argues that the lived experience for persons with autism in a PNT society that doesn’t readily understand them does, therefore, often result in a disadvantaged outcome (Beardon, 2017). In developing this principle Beardon wrote:

Much of the literature debates whether autism should be viewed as a disability, a difference, something that should be cured, or maybe something that can be seen as an advantage in some circumstances. In reality, autism is different for each autistic person, while there are some common characteristics (2017, p17).

Beardon (2017) goes on to argue that viewing persons with autism as impaired, disordered, or disabled is problematic particularly when many persons with autism don’t identify with such labels (O’Neill, 2008; Schafer, 2009; Downing, 2014; Shattuck et. al., 2014; Rutherford, Butcher, and Hepburn, 2016) and that the lived experience is different for each person with autism. Beardon writes (2017, p1), “There is no such thing as a ‘typical autistic person’¹²”. Other authors have also argued that when you have met one person with autism, you have only met one person with autism (National Autistic Society, 2016; Chown, 2017). Similarly, Orsini and Davidson (2013, p12) refer to the “kaleidoscope complexity of this highly individualised relational (dis)order”. I agree with these authors that each person with autism is a unique individual whose lived experience is exclusive to them. In addition, for me, how a person with autism

¹² I acknowledge that there’s also no such thing as a typical PNT person.

interprets and responds to the world not only varies between individuals but within individuals over time¹³. Also, as stated by Gerland:

In addition to the triad of impairments you could say that what characterises the autism spectrum is a significant unevenness in development. This means that in practice a person can be of many ages. The individual can in one area be far ahead of their peers, in another just like their peers and in a third area far behind their peers (Gerland, 2013, p144).

Having examined the social model of disability understanding of autism I now summarise how this has influenced my theoretical position.

2.4.3 Summary

From the perspective of many academics and as I have outlined in relation to my perspective, the social model of disability ideology posits that persons with autism are disabled by the attitudes of individuals in society, the environmental factors that these inform, and the social barriers that result (Oliver, 1983). The neurodiversity movement originally extended the social model of disability to understandings of cognitive difference and positions the autism neurotype as one of many natural variations of the human (Jaarsma and Wellin, 2011). Furthermore, as a result of the PNT society that persons with autism inhabit, that doesn't really understand them, persons with autism are recognised as frequently having a disadvantaged outcome (Beardon, 2017).

This alternative understanding of autism, for me, presents possibilities for an enabling narrative of sociality and friendship for persons with autism that facilitates a challenge to the binary of autistic and PNT sociality and, therefore, to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). The social model of disability thinking, therefore,

¹³ I acknowledge that this interpretation and response to the lived experience also varies for the PNT.

aligns with my aim for the outcome of my research to contribute to resolving the conundrum I have observed in my son and found support for in the literature.

I acknowledge that the social model of disability has been subject to criticism, e.g., from disability charities, medical professionals, and academic researchers including persons with disabilities and autism and I recognise that persons with disabilities remain subject to social oppression (Tregaskis, 2002; Shakespeare and Watson, 2002; Oliver, 2013; Mallet and Runswick-Cole, 2014). Oliver (2013), the author credited with conceptualising the social model of disability, has argued he didn't "claim that the social model was an all-encompassing framework within which everything that happens to disabled people could be understood or explained" (2013, p1024). However, in the context of my research, the social model of disability ideology presents possibilities for an enabling narrative of sociality and friendship for persons with autism that aligns with my theoretical position.

As I have previously stated, the perspective of many academics and, for me, the dominant understanding of autism in our society is based on the medical model of disability ideology that prefers and privileges PNT sociality and friendship over that of persons with autism. This predilection has arisen due to the power imbalance between the majority PNT population and persons with autism, a minority population that results in their disadvantaged outcome (Beardon, 2017). One of the elements of critical autism studies (CAS) is considering how power relations influence autism research (Davidson and Orsini, 2010). CAS presents another way of understanding autism that I argue supports the aim for the outcome of my research that I now examine.

2.5 Critical autism studies (CAS) understanding of autism

Critical autism studies (CAS) was first conceptualised in 2010 (Davidson and Orsini, 2010) and consists of three main elements:

- 1) Careful attention to the ways in which power relations shape the field of autism

- 2) Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture
- 3) Commitment to develop new analytical frameworks using inclusive and nonreductive methodological *and* theoretical approaches to study the nature and culture of autism (Orsini and Davidson, 2013, p12).

As a complimentary field to critical disability studies¹⁴ with a focus on researching autism:

Critical autism studies also troubles the commonsense understanding of (dis)ability through interrogation of the construction of autism as a spectrum of difference configured as social and cognitive impairments, which may sit uneasily within a (dis)ability framework (O'Dell et. al., 2016, p168).

Furthermore, CAS rejects pathologising references to the 'norm' as society's worldview (O'Dell et. al., 2016). Oliver stated (1992, p101), "Disability cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it". Autism, one such label of disability, can, therefore, be conceptualised from the perspective of social constructionism, i.e., it's for society to redefine the boundaries of normality¹⁵ to include persons with autism. This I believe will contribute to the removal of social barriers and facilitate the integration of persons with autism into society.

¹⁴ Disability studies emerged from the 1980s across much of the western world, is based on the social model of disability and the rejection of disability as being the fault of the individual (Ferguson and Nusbaum, 2012). Critical disability studies (CDS) subsequently developed from the turn of the 21st Century. The objective of CDS is to deconstruct established narratives and ideologies about disability and disrupt the impaired versus non-impaired dualism (Vehmas and Watson, 2014).

¹⁵ I acknowledge that the existence of the concepts of normal and normalcy is a matter of debate in the academic community (e.g., Titchkosky and Michalko, 2009). However, a detailed critique of this debate isn't within the scope of my thesis.

Other authors presented conceptualisations of autism that challenged the dominant notion of normality and this medical model of disability discourse. Sinclair (1993, p1) stated, “Autism is a way of being”, and Chamak (2007, p76) described persons with autism as “individuals with a different cognitive mode of functioning”. McGuire and Michalko (2011) didn’t view autism as a puzzle that required solving. Instead, these authors viewed persons with autism as examples of “the fundamental human features of uncertainty, of the incompleteness and partiality of communication” and “as a reminder that we live in the risk of incompleteness” (McGuire and Michalko, 2011, p164).

In summary, from my perspective and that of many academics, CAS aims to advance a challenge to the dominant medical model of disability understanding of autism that I have previously stated doesn’t provide a suitable framework for my research and that I must reject (see section 2.3.5). Similarly to the social model of disability, for me, CAS presents possibilities for an enabling narrative of autism that advances a challenge to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). In particular, this understanding of autism rejects the PNT point of reference as society’s norm facilitating the deconstruction of the binary of autistic and PNT sociality in terms of the “taken-for-granted assumptions of formal/informal social competencies” (O’Dell, et. al., 2016, p169). CAS thinking, therefore, aligns with my aim for the outcome of my research to contribute to resolving the conundrum of persons with autism socialising but finding it difficult to make friends and maintain friendships.

In sections 2.3 to 2.5, I have presented my position regarding the different understandings of autism in the literature of relevance to my focus of enquiry. I now conclude this section of my literature review by presenting an overview of my theoretical position.

2.6 My theoretical position

As I stated in section 2.2, my theoretical position must present possibilities for

an enabling narrative of sociality and friendship for persons with autism that: 1) deconstructs the binary of autistic and PNT sociality, and, therefore, advances a challenge to this dominant discourse on sociality and friendship and; 2) argues for a range of sociality and friendship possibilities across being human. To do so, I argue, I need to describe in my research the meaning of sociality and friendship of persons with autism from their perspective. I must, therefore, reject the medical model of disability ideology understanding of autism that I have examined in sections 2.3 that is based on the PNT perspective as the ideal state of being human (Mallett and Runswick-Cole, 2014), positions persons with autism in comparison as being deficient and impaired (APA, 2013b) and has, therefore, from my perspective constructed the binary of autistic and PNT sociality.

Instead, my theoretical position is supported by the alternative understandings of autism I examined in sections 2.4 and 2.5 that argue for a range of sociality and friendship opportunities across being human, i.e., the social model of disability (Oliver, 1983) including the theory of disadvantage that acknowledges the frequently disadvantaged outcome of persons with autism in a PNT dominated society (Beardon 2017). In addition, the neurodiversity movement that recognises the autism neurotype as a natural variation of the human (Singer, 1999) and the principles of CAS that seeks to advance a challenge to the dominant medical model of disability understanding of autism (Davidson and Orsini, 2010).

I now turn my attention in sections 2.7 to 2.12 to interpreting through the lens of my theoretical position the key concepts of relevance to my focus of enquiry. I begin by exploring the concept of Theory of Mind (ToM), the key psychological theory associated with the meaning described by persons including those with autism of sociality and friendship (Sigman and Ruskin, 2001; Bauminger, Solomon, and Rogers, 2010; Hotton and Coles, 2016).

2.7 Theory of mind

As described in the studies of Heider and Simmel, the ability of people to ‘mind

read' or recognise emotions in people has been the subject of psychological research since the 1940s¹⁶ (Rajendran and Mitchell, 2007). In the 1960s and 1970s, autism research focused on the development of psychological theories (Howlin, 1998). Research theorised autistic features in older children, adolescents, and young adults. The focus of enquiry was to identify the neurological cause(s) of autism (Bishop, 2008; O'Dell et. al., 2016) and investigate the psychology of how persons with autism thought, felt, and perceived their environment and experiences. One such psychological theory was (ToM) (Baron-Cohen, 1995).

ToM is the ability to attribute mental states including desires, beliefs, and action to oneself and others (Baron-Cohen, 1995) and serves as the foundation enabling someone to navigate the social world and form relationships including friendships (Brandone, 2016). As stated by Chown (2014, p1672), "There appears to be an assumption made by most authors who write about ToM in autism that it is an autistic person's ToM difficulties which precede the social difficulties they face". Hacking (2009, p1467) writes ToM is "not the common property and practice of people with autism". In doing so, this author and others who adopt this perspective have positioned the sociality and friendship experiences of persons with autism as lesser and other in comparison to the PNT norm. Autism is, therefore, often regarded as a relational disorder that I now examine.

2.7.1 Autism as a relational disorder

Autism "disrupts emotional interactions with others" (Davidson and Orsini, 2010, p131). Research into the sociality of persons with autism often proposed that their inability to form relationships similar to those formed by the PNT was due to a lack of, delayed, or underdeveloped ToM (Bauminger, Solomon, and Rogers, 2010). These authors stated that the friendships of children with autism differed in quality and quantity due to deficits in ToM. Other research concluded that children with autism don't generally display reciprocal social behaviour

¹⁶ Researching theory of mind hasn't been confined to the field of autism, but has been undertaken in a variety of psychological contexts.

(Baron-Cohen, Leslie and Frith, 1985; Downs and Smith, 2004). Hotton and Coles (2016) cited research that claimed it was a lack of ToM that accounted for persons with autism initiating fewer social interactions. Research into ToM, therefore, has sought to explain the difficulties with relationships of persons with autism.

Other authors have, however, challenged the assumption that ToM difficulties precede the social difficulties that persons with autism face. As proposed by Chown (2014 and 2017), whilst persons with autism were expected by society to understand PNT sociality and develop a PNT ToM, the PNT weren't expected to acquire an understanding of autistic sociality or develop an autistic ToM. Milton (2012) concluded that:

One could say that many autistic people have indeed gained a greater level of insight into non-AS society, and more than *vice versa*, perhaps due to the need to survive and potentially thrive in a non-AS culture. Conversely the non-AS person has no pertinent personal requirement to understand the mind of the 'autistic person' unless closely related socially in some way (Milton, 2012, p886).

Beardon (2008b) shares this perspective of Milton (2012; 2014) on the power imbalance between the PNT and persons with autism that has resulted in this disadvantage. This author argued that the emphasis is on the person with autism to change their autistic sociality to be more like that of the PNT and there is no corresponding requirement for the PNT to do the same.

It may be that the PNT have as much difficulty in understanding the mind of a person with autism as *vice versa* and this is indicative of the double empathy hypothesis of Milton (Milton, 2014) and the cross-neurological ToM concept of Beardon (Beardon, 2008b; 2017). Both these authors theorise that persons with autism don't lack a ToM, rather that there is a lack of a ToM of the others' neurological state. Furthermore, it isn't that people with autism or the PNT are better at developing an understanding of the other's sociality. The necessity to do so in a PNT society, according to these authors, lies with persons with autism, who as the minority group have been placed at a disadvantage if they

are to survive and prosper. My understanding, therefore, is that the alleged lack of sociality of persons with autism is a false construct and as argued by Beardon (2015) a myth.

Having examined these differing understandings of ToM in the context of the sociality of persons with autism I now summarise how I interpret them through the lens of my theoretical position.

2.7.2 Summary

Research into the sociality of persons with autism has proposed their inability to form relationships similar to those formed by the PNT is due to a lack of, delayed, or underdeveloped ToM (Bauminger, Solomon, and Rogers, 2010). This understanding of autism has, for me, resulted in the binary of autistic and PNT sociality and contributed to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). In addition, I believe that research that posits ToM difficulties precede social difficulties in autism has also perpetuated the conundrum of socialising and finding it difficult to make friends and maintain friendships. Furthermore, it fails to present possibilities for an enabling narrative of sociality and friendship for persons with autism. I must, therefore, reject this medical model of disability theoretical perspective that assumes a non-autistic norm and proposes that ToM difficulties in persons with autism precede their social difficulties (Chown, 2014).

In contrast, for me, the cross-neurological ToM concept (Beardon 2008b; 2017) and the double empathy hypothesis (Milton, 2012; 2014) present possibilities for an enabling narrative of sociality and friendship for persons with autism that advances a challenge to the binary of autistic and PNT sociality, and, therefore this dominant discourse. The cross-neurological ToM concept (Beardon 2008b; 2017) and the double empathy hypothesis (Milton, 2012; 2014) also challenge the assumption of a non-autistic norm. These theories I argue align with my aim for the outcome of my research to contribute to resolving the conundrum of

persons with autism socialising and finding it difficult to make friends and maintain friendships.

Beardon writes (2017, p18), “Changes in attitude, adjustments, and understanding within society can go a long way to reduce the disadvantages autistic adults frequently face”. Changes in the PNT understanding of the sociality of persons with autism may present possibilities for an enabling narrative of sociality that I now explore.

2.8 Sociality

Sociality has been the subject of extensive academic research. Humans are sociable by nature, and the most striking characteristic of the human is its unique sociality (Paige-Fiske, 1992; Haslam et. al., 2009). What sets human sociality apart from other species is distinctive properties that include cooperation, morality, and its’ complex structured nature (Enfield and Levinson, 2006). Sociality can be defined as “consisting of a range of possibilities for social coordination with others that is influenced by the dynamics of both individuals and social groups” (Ochs and Solomon, 2010, p69). This inherent characteristic of the human is rooted in the advantages afforded to our ancestors of sociality in terms of survival, economic production, and the creation of knowledge that could be passed on to subsequent generations. Today, social relations are an integral part of every aspect of a person’s daily life, in work, education, and leisure, and are rich and diverse. Sociality has allowed humans to survive and prosper and is also a pivotal factor in the general well-being of individuals (Haslam et. al., 2009).

The origins of researching sociality lie in interdisciplinary studies, psychology, philosophy, sociology, and anthropology (Antonucci, Ajrouch, and Birditt, 2014). The ancient Greek philosophers regarded sociality as an intrinsic part of the human. Aristotle stated, “Man is by nature a social animal” (Brzezicka and Wisniewski, 2014, p356). The key academic theories in the literature that underpin the concept of social relationships or sociality are:

- The 'theory of motivation' and the 'hierarchy of needs' (Maslow, 1943). The third level of the hierarchy, the social need, is the desire for persons to feel loved and to belong. The social need includes friendships, intimacy, affection, and love, and is met through relationships at work, with family members, friends, and partners (McLeod, 2007)
- Social exchange theory (Emerson, 1976). Individuals choose to form the relationships they perceive as being in their best interests (Cropanzano and Mitchell, 2005). The exchange between individuals is described in terms of emotional support and interaction. Individuals assess the perceived benefits and risks of a relationship and pursue or maintain a friendship when the rewards outweigh the costs. The ability to make rational choices is implicit with relationships being regarded as an essential aspect of living in a society (Cropanzano and Mitchell, 2005)
- The concept of self (Sedikides, Gaertner, and O'Mara, 2011). As described by these authors, there are three representations, the individual, relational, and collective self. The individual self is concerned with the uniqueness of a person. The focus of the relational self is with forming relationships with individuals who have similar characteristics. Individuals achieve the status of the collective self by belonging to large groups and contrasting the defining features of these collectives to those of other groups.

Humans are, therefore, inherently sociable (Page-Fiske, 1992; Haslam et. al., 2009). However, the dominant medical model of disability conceptualisation of autism that I rejected in section 2.3.5 posits persons with autism as having impaired sociality and, therefore, within the dis/human (Goodley and Runswick-Cole, 2016). I now explore how this view of sociality has arisen.

2.8.1 The PNT view of sociality

As previously described in section 2.3.4, the diagnostic criteria for autism claim that persons with autism have impaired sociality (Kanner, 1943; Wing, 1996; WHO, 2010; APA, 2013b). However, for me, the impairments described in the

diagnostic criteria have been conceptualised from the perspective of the PNT; in other words through the lens of PNT sociality. In the literature, the sociality of persons with autism was subject to multiple comparisons to the PNT experience:

The expectations of social behaviour are all defined by NT¹⁷ researchers assuming NT functioning of the people they are studying. The experiences of autistic people are largely absent or rendered 'abnormal' through such research (Bertilsdotter Rosqvist, Brownlow, and O'Dell, 2015, no page number).

In addition, persons with autism were found in comparison to their PNT peers to make and accept fewer social approaches (Sigman and Ruskin, 1999), didn't listen to others (Carrington and Graham, 2001), didn't know from a PNT perspective how to approach persons (Daniel and Billingsley, 2010), or were positioned as being less socially motivated to make social contact (Bauminger, Shulman, and Agam; 2003; Sedgewick et. al., 2016). Other social interaction difficulties included recognising facial expressions, making appropriate eye contact, and maintaining joint attention (Hotton and Coles, 2016).

This external PNT view is embedded in the medical model of disability ideology that as stated by Grinker has resulted in (2015, p345) "neglecting the possibility for new forms of sociality to emerge, and diminishing the role that autism can play in forming new social identities". From my perspective, and that of many academics, the PNT perspective posits persons with autism as having impaired sociality and is indicative of the medical model of disability ideology that I have rejected. I must, therefore, also reject the PNT understanding of the sociality of persons with autism that doesn't present possibilities for an enabling narrative.

I now examine the meaning of sociality as described by persons with autism through the lens of my theoretical position and consider whether this meaning aligns with my understanding of autism.

¹⁷ NT is an abbreviation of neurotypical and is an alternative term to PNT.

2.8.2 The person with autism view of sociality

Edmonds and Beardon write (2008b, p19), “Sociability has nothing whatsoever to do with intuitive social understanding – I suspect the same range of sociability (i.e., need for and wanting social relationships – friends, relationships) is similar to that of the NT population”. The published literature described many examples of the sociality of persons with autism (Cornish, 2008; Shepherd, 2008; Bagatell, 2010; Ochs and Solomon, 2010; Sinclair, 2005 and 2010; Conn, 2015 and 2016). Bagatell (2010, p39) wrote, “One of the biggest surprises for me was discovering the highly social nature of AACT¹⁸. However, socialising at AACT meetings involved practices that I did not originally perceive as social”. These unanticipated social practices included monologues, ramblings about a personal interest (that were seemingly ignored by other persons in the group), using complex humour, interactive stimming¹⁹ experiences, and the silent sharing of physical space. To socialise with other people, one of the participants explained, “We don’t have to talk. We can just share energy to be social” (Bagatell, 2010, p40). Similarly, Bertilsdotter Rosqvist, Brownlow, and O’Dell (2015) described an example of persons with autism being silent when in the company of friends. Sinclair (2010) stated that some persons with autism didn’t need to participate in an interaction to feel that they were being sociable.

Other examples of sociality were persons with autism needing more alone time compared to most of the PNT, needing constant interaction to a degree that exceeded that of the most extrovert PNT (Sinclair, 2010), or being engaged in a solitary activity with other persons present in the background (Conn, 2016). This author described how a person with autism “could share physical sensation” with a friend without speaking (Conn, 2015, p1200).

¹⁸ AACT is an abbreviation of Autism Adults Coming Together. This was the name given to the group run by adults with autism that the researcher was studying.

¹⁹ Stimming is a self-stimulatory behaviour and examples are hand flapping, body spinning, or rocking (Bagatell, 2010).

Cornish (2008) described how he socialised on an intellectual rather than on a PNT social level. This author stated that his loyalties lay with the truth and not with the feelings or thoughts of individuals. The result was an honest answer to a question that didn't take into account the emotional needs of the person who asked it. Similarly, Shepherd (2008) referred to being brutally honest about not wanting to continue a conversation about a subject that didn't interest him.

The meaning described by persons with autism of their sociality, therefore, for me, presents an alternative understanding to the PNT perspective and the possibility of an enabling narrative that aligns with my theoretical position. In summary, from my review of the literature, the sociality of persons with autism was found to display: 1) less frequent examples of common PNT social behaviours; and 2) social behaviours that weren't commonly associated with the PNT. I now consider how these social behaviours of persons with autism argue for a range of sociality possibilities across being human.

2.8.3 Shared behaviours of the PNT and persons with autism

Autism is often described and understood in terms of behaviour (Beardon, 2017). However, whilst a person can only be of one neurotype, of which autism is one, and the PNT is another, there is no such thing as typical autistic behaviour or a definitive set of behaviours that is exclusive to persons with autism or the PNT (Beardon, 2017). Whilst there are behaviours that are more likely to be observed in persons with autism such behaviours can also be found to a lesser extent in the PNT (Langen et. al., 2011; Barrett, et. al., 2015; Beardon, 2017). Beardon (2017, p19) suggests that "We understand autism as a differing neurotype that will have an impact on how the individual might behave – but that we can't assume that the behaviour in turn 'makes' the person autistic".

There is, therefore, an overlap of behaviours described by persons of both neurotypes. Examples of these shared behaviours are arranging items in rows or patterns, repetitively fiddling with, or having a special interest in particular objects. Other shared behaviours include a person spinning themselves,

rocking back and forth, pacing around, or making repetitive hand movements (Barrett, et. al., 2015). Examples of social behaviours that are more commonly found in persons with autism are stimming (Bagatell, 2010), the silent sharing of physical space (Bertilsson Rosqvist, Brownlow, and O'Dell, 2015), being engaged in a solitary activity with other persons present in the background (Conn, 2016), or talking at length on a specific subject regardless of the interest of the persons around them (Ochs and Solomon, 2010). However, I argue that whilst more likely to be observed in persons with autism these behaviours can also be found to a lesser extent in the PNT. There is, therefore, an overlap of behaviours described by persons with autism and of the PNT (Beardon, 2017).

I acknowledge that some persons with autism and the PNT, including authors and researchers, may disagree with my understanding of the concept of shared behaviours and instead argue for a different autistic sociality (e.g., Bagatell, 2010; Ochs and Solomon, 2010; Sinclair, 2010; Milton, 2014; Conn, 2015). However, from my perspective I argue that this isn't an enabling narrative for persons with autism as it doesn't advance a challenge to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). The concept of autistic sociality, therefore, that I must reject doesn't argue for a range of sociality possibilities across being human and doesn't align with my theoretical position.

Having described the concept of shared behaviours of the PNT and persons with autism that I support I now summarise through the lens of my theoretical position the different understandings of sociality that I have examined in this section.

2.8.4 Summary

Humans are sociable by nature, and the most striking characteristic of the human is its unique sociality (Paige-Fiske, 1992; Haslam et. al., 2009). In the literature, the sociality of persons with autism was subject to multiple comparisons to the PNT experience that positioned their sociality as impaired

and within the dis/human (Goodley and Runswick-Cole, 2016). This predominance of the external or PNT view of a different autistic sociality is from my perspective, and of some academics, embedded in the medical model of disability ideology. I have already rejected this ideology that doesn't present an enabling narrative of sociality for persons with autism. I must, therefore, also reject the PNT view of the sociality of persons with autism. In contrast, the meaning described by persons with autism presents an understanding of sociality that, for me, argues for a range of sociality possibilities across being human that aligns with my theoretical position.

My understanding is that there is no such thing as typical or exclusive autistic behaviour. Instead, in common with other academics (e.g., Beardon, 2017) I posit there are shared behaviours common to both neurotypes that overlap with some being more likely to be observed in persons with autism than the PNT. For me, recognising this overlap of behaviours will contribute to deconstructing the binary of autistic and PNT sociality and, therefore, facilitate a challenge to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). Recognising shared behaviours between persons with autism and the PNT, therefore, aligns with my aim for the outcome of my research to contribute to resolving the conundrum of persons with autism socialising but finding it difficult to make friends and maintain friendships. I now explore different understandings of friendship through the lens of my theoretical position.

2.9 Friendship

Friendship in the literature was described as being ubiquitous in nature, a vital aspect of society (Mauk, 2011), and the human relationship of the greatest importance (Salmon, 2013). This phenomenon has been the subject of academic discourse since the ancient Greeks.

Historically, academic disciplines have made the phenomenon of friendship their focus of inquiry to differing degrees and timescales and from different

perspectives (Bagwell and Schmidt, 2011). The philosophical definition of friendship is based on intimate relationships and acknowledges different types of friendship: pleasure, utility, and virtue (Helm, 2013). As described by this author, the phenomenon of friendship from a philosophical perspective is also reciprocal in nature, can only be experienced by two people, and has a moral dimension. Psychology has focused on researching social relationships and definitions of this phenomenon share several characteristics, i.e., friendship is between two people and involves the mutual sharing of feelings and experiences that have an intrinsic value for the individuals in the relationship (Bagwell and Schmidt, 2011).

Sociology and anthropology have recently embraced friendship as a focus of enquiry (Beer, 2001; Holmes and Greco, 2011). A sociological definition of friendship is, therefore, modern. It describes a voluntary relationship between individuals with equality, reciprocity, mutual goodwill, affection, and/or assistance. Unlike other disciplines sociology recognises the environment shapes friendship regarding it as a social practice (Holmes and Greco, 2011). For anthropology, friendship contains salient features such as informality, choice, mutuality, trust, affection, sharing, and loyalty (Beer, 2001). Uniquely, as stated by this author, anthropology acknowledges that friendship has different meanings in different cultures (Beer, 2001).

There are, therefore, numerous definitions of friendship, but no single or even widely agreed one (Rybak and McAndrew, 2006). Friendship I have observed remains something that most of us claim to desire and experience and is the subject of frequent discourse but remains difficult to describe. Each discipline has various definitions of friendships but doesn't propose a single meaning and brings something unique to the understanding of this phenomenon. Identifying commonality between the definitions of friendship presented by the different disciplines was, for me, problematic. However, the literature suggested that a PNT perspective presented a definition of friendship as being exclusively between people, involved the sharing of a practical or an emotional experience, and is valued by at least one of the individuals in the relationship (Bagwell and Schmidt, 2011; Helm, 2013).

Similarly to the research that has been conducted of the sociality of persons with autism (see section 2.8.1), friendship has also been researched predominantly from the perspective of the PNT that I now explore.

2.9.1 The PNT perspective of friendship

Meyer and Ostrosky (2014) researched the published literature over the last thirty-five years to determine what had been learnt regarding the friendships of young children with disabilities including autism. Children with disabilities were found to have had friends, and their friendships were similar in the qualities and characteristics identified by PNT children of a similar age. Despite these similarities Meyer and Ostrosky concluded:

Children with developmental delays or certain disabilities such as intellectual disabilities, autism, communication disorders, challenging behaviours, and hearing impairments interact with persons less often and tend to have a lower social status, which can influence whether friendships will develop (2014, p195).

Other authors have suggested that whilst persons with autism do desire and participate in friendship they found friendship difficult (Bauminger and Kasari, 2000; Jones and Meldal, 2001; Daniel and Billingsley, 2010; Mendelson, Gates, and Lerner, 2016). Neysa, Carter, and Stephenson (2014) undertook a review of twenty-four studies that addressed the characteristics of friendship in school children with autism. They claimed, “These data suggest that there are important differences in the manifestation of friendships in individuals with ASD²⁰ as compared to typical children” (p122). Differences included the children with autism having fewer friends, shorter, and less stable friendships of poorer quality, and difficulty in defining friendship. Orsmond, Wyngaarden-Krauss, and Seltzer (2004) concluded that the more severe the impairments of persons with autism, the less likely they were to make friends and Salmon writes (2013, p347), “Disability complicates experiences of friendship”. Brownlow, Bertilsdotter Rosqvist, and O’Dell (2015) stated that persons with autism are assumed to be unable to form relationships, or are in need of

²⁰ ASD is an acronym for autistic spectrum disorder.

educational interventions to be better equipped at managing relationships in a social world dominated by the PNT.

As with the concept of PNT sociality that I explored in section 2.8.1, the PNT perspective of friendship, for me, posits persons with autism as having impaired friendships and positions them within the dis/human (Goodley and Runswick-Cole, 2016). This PNT view of the friendship of persons with autism is embedded in the medical model of disability ideology that I have previously rejected. I must, therefore, reject this PNT perspective of this phenomenon as it fails to present an enabling narrative and doesn't align with my theoretical position. There is, however, a limited amount of research examining the nature of relationships of persons with autism from their perspective that I now examine (Neysa, Carter, and Stephenson, 2014; Brownlow, Bertilsdotter Rosqvist, and O'Dell, 2015).

2.9.2 The person with autism perspective on friendship

When persons with autism had been able to make friends and maintain friendships they viewed this as a positive lived experience. Carrington, Templeton, and Papinczak (2003) researched the aspirations of friendship in secondary school for five teenagers with AS. They claimed, "Equally significant is the satisfaction expressed by these teenagers with many of their friendships. The participants spoke of feeling comfortable with friends, and of shared interests and activities" (p19). Calder, Hill, and Pelicano (2012) found that the children with autism in their study were satisfied with their friendships. Brooke, Cohn, and Orsmond (2006) also concluded that the children with autism in their study enjoyed friendships and were interested in this phenomenon.

The PNT perspective of friendship assumes that a friend is a person (Bagwell and Schmidt, 2011; Helm, 2013). However, persons with autism also talked about their experiences of friendship as also being with animals, objects, or activities (Davidson and Smith, 2009; Gardner, 2012; Grandgeorge et. al., 2012; Wrongplanet, 2012; Slavin, 2015; Conn, 2015 and 2016). I acknowledge there is a debate in the academic community about the plausibility of animals as

friends (Townley, 2011) and this is dependent on how a person conceptualises friendship. However, research has found that children with autism were attached to their pets and had a bond with them that could be described as friendship (Carlisle, 2015). The arrival of a pet in a home has also been found to increase the sociality of children with autism (Grandgeorge et. al., 2012). In *A friend like Henry* (Gardner, 2008), the dog, Henry, became a friend for a boy with autism. Davidson and Smith (2009) described persons with autism who thought of their cats as friends.

Grandin stated that (1995, p132), "Friendship always revolved around what I did rather than who I was". Williams (1992) wrote of her strong attachment to the objects owned by other people and said, "In my visually fragmented, faceblind world, my reflection was my best friend" (Williams, 2016). Persons with AS posting on a website forum talked about stuffed animals or machines being their best friend (Wrongplanet, 2012). Other online posts included mourning the loss of a chair as if it had been a friend (Slavin, 2015). This blogger described how he felt sympathy for inanimate objects, as he would for a friend's misfortune, such as photographs pushed to one side, musical instruments that were no longer played, or the replacement of a camera with a newer model. The comments on this website (Adultswithautism, 2015) posted by persons with autism, stated that they too had experienced similar feelings of empathy or friendship for objects throughout their lives.

Prince-Hughes (2004) described that when moving house as a child she felt she was betraying objects by not keeping them. Conn (2015, p1197) wrote of the engagement of persons with autism with "non-toy objects" such as coins spinning and how objects were experienced as being alive and animated. Davidson and Smith (2009) found that some persons with autism had continuing relationships with animals and objects that were just as or more than important to them as their relationships with people. The meaning described by persons with autism of friendship, therefore, presents the possibility of an enabling narrative that aligns with my theoretical position.

Having examined these differing understandings of the friendship of persons with autism I now summarise my position regarding this phenomena in terms of my theoretical position.

2.9.3 Summary

Friendship in the literature was described as being ubiquitous in nature, a vital aspect of society (Mauk, 2011), and the human relationship of the greatest importance (Salmon, 2013). Friendship has been researched predominantly from the perspective of the PNT with the definition of this phenomenon being exclusively between people (Bagwell and Schmidt, 2011; Helm, 2013). For me, the PNT perspective posits the friendship experiences of persons with autism as impaired and within the dis/human (Goodley and Runswick-Cole, 2016) and has also contributed to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). From my perspective, research that posits that friends must be persons excluding objects and animals has also perpetuated the conundrum of socialising but finding it difficult to make friends and maintain friendships. Furthermore, it fails to present possibilities for an enabling narrative of friendship for persons with autism. I must, therefore, reject this PNT medical model of disability theoretical perspective that assumes the friendships of persons with autism are impaired in comparison to the PNT.

In contrast, for me, the meaning of friendship described by persons with autism presents an alternative understanding of friendship that advances a possible challenge to the dominant discourse. The understanding of friendship described by persons with autism aligns with my aim for the outcome of my research, i.e., to contribute to resolving the conundrum of persons with autism socialising and finding it difficult to make friends and maintain friendships and presents possibilities for an enabling narrative of friendship for persons with autism.

I now turn my attention in sections 2.10 to 2.12 to interpreting through the lens of my theoretical position the concepts of normalcy and ableism. For me, these

concepts represent the disabling social barriers that persons with autism encounter in the meaning they describe of sociality and friendship. I begin by exploring the concept of normalcy.

2.10 Normalcy

Davis (2013) described how the concepts of 'normal' and 'normalcy' have developed in western society that I now present. The word 'normal' entered the English language in around 1840 and normalcy in 1857. Normal can be defined as "constituting, conforming to, not deviating or different from, the common type or standard, regular, usual" (Davis, 2013, p1). Statisticians in the 19th century introduced the notion of normality. This resulted in the concept of normalcy, which had previously been the preserve of the scientific community, being applied to human characteristics. Prior to this it was the concept of the ideal that prevailed. In terms of the human body, the ideal was the preserve of the Gods that was thought of as unachievable by the human (Davis, 2013). The concept of normalcy changed this perception. Normalcy introduced a construct that wasn't only obtainable but was also the correct and preferred way of being to be exhibited by the majority of the population (Abberley, 1987). This paradigm shift from the ideal to the normal introduced the concept of deviations or the extremes of being, the dis/human (Goodley and Runswick-Cole, 2016).

Some statisticians were also eugenicists who aimed to reduce deviations from the norm and realise a perceived improvement in the human population (Davis, 2013). As described by this author, eugenicists pursued the elimination of so-called 'deviants' that included persons with impairments or disabilities. Eugenics in the western world was practised into the 20th century. The predominant social discourse and cultural embodiment of persons with disabilities in western society became dis/human a "tragedy, the impaired body and Otherness" (Stone and Priestley, 1996, p699). Stereotypes of persons with disabilities documented in the literature included objects of violence, ridicule, and curiosity, regarded as pitiable, pathetic, dangerous, a burden, sexually abnormal, incapable, or their own worst enemy (Barnes, 1992).

Normalcy positions the PNT lived experience of any social phenomenon, including sociality and friendship, as the only life worth living (Michalko, 2009). Persons with disabilities were held responsible for their 'deficits' and were required to explain their extraordinary bodies to the PNT to justify their existence. Michalko (2009, p69-70) wrote, "Theorising disability is one way of removing disability from the place of normalcy, which understands disability as Other, to the place of valued life which experiences disability as Alter". This author regarded disability as a different but not a lesser form of being. Titchkosky (2009) suggested that it's in the imagination where disability begins. Disability isn't a constant but a changing construct based on the social and political ideology of the time. This author wrote that disability is viewed through the lens of cultural assumptions and that this resulted in the societal view that certain differences are labelled as disabilities. Disability is, therefore, an infrequently acknowledged "inescapable element of human existence and experience" (Couser, 2005, p602).

Persons with disabilities make up a significant proportion of the population²¹. The boundary between disabled and non-disabled is fluid as anyone can become disabled at any time through illness or injury, or through medical treatments and rehabilitation can relinquish their label. From my perspective, the perpetuation by our society of the concept of normalcy is, therefore, not sustainable. Aligned to the notion of normalcy is the concept of ableism (Hodge and Runswick-Cole, 2013). In the following section, I explore how ableism may have contributed to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014).

²¹ In Great Britain, the government estimated in 2014 there were over eleven million people with a limiting long-term illness, impairment, or disability. This represented 6% of children, 16% of working age adults, and 45% of adults over state pension age with disabilities (Great Britain, Department for Work and Pensions and Office for Disability Issues, 2014).

2.11 Ableism

Ableism evolved from the disability rights movement in the mid- to late-20th century. Campbell defined ableism as:

A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human (2009, p5).

Ableism is negative and discriminatory as it prefers and privileges one form of the human, the PNT person over that of another, the person with disabilities, or in the context of my research with autism (Linton, 1998). Other authors have argued that today's society desires ontological security or confidence in the nature of the social world and this concept is challenged by disability (Campbell, 2009). For me, persons with disabilities who don't conform to the ableist norm are, therefore, subject to exclusion and oppression being viewed as the 'Inferior Other'. Ableism is aligned with the medical model of disability in that this concept "constructs [certain] bodies as 'impaired' and positions these as 'Other': different, lesser, undesirable, in need of repair or modification and de-humanised" (Hodge and Runswick-Cole, 2013, p312).

From my perspective, if persons with autism are regarded by the PNT as the "inferior Other" their meaning of sociality and friendship may not be regarded as credible and misconceptions regarding their lived experience may arise. Jones and Medal concluded (2001, p40), "It appeared that there is a desire for social relationships but that these relationships are regarded as difficult, confusing and ultimately frightening to people with Asperger's". Authors claimed that the difficulty that persons with autism experience in establishing friendships resulted in few friends (Chamberlain, Kasari, and Rotheram-Fuller, 2006; Bauminger, et. al., 2008a; Neysa, Carter, and Stephenson, 2014). Carrington, Templeton, and Papinczak found that for persons with AS (2003, p17) "Social difficulties influence the development and maintenance of friendships and social contact with peers".

The social approaches made by persons with autism may, I posit, be misinterpreted by the PNT, i.e., unconventional social approaches that don't conform to the aspirational markers of ableism may have been misunderstood as disinterest in friendship. Carrington, Templeton, and Papinczak (2003) wrote that adolescents have a need to fit in. They found that adolescents with AS were unable to fully understand social situations and, therefore, couldn't achieve social acceptance. Other authors reported persons with autism having similar experiences regarding their lack of social acceptance by the PNT (Roantree and Kennedy, 2012; Roud, 2013). Church, Alisanski, and Siraj (2000) researched the experiences of forty children with AS. These children were described by the PNT as "silly", "rude", or "very inappropriate". Laughing too hard at jokes, blurting out socially inappropriate comments, saying unintentionally hurtful things, or behaving in ways far less mature than expected" (2000, p16).

Other research highlighted the limited opportunities available to persons with autism to engage in friendships (Brewin, Renwick, and Schormans, 2008). The assumption that friendship wasn't desired or needed led to few settings and environments for persons with autism to socially interact and experience friendship. Orsmond, Wyngaarden-Krauss, and Seltzer stated (2004, p253), "Very few adolescents and adults with autism were reported to have friendships with same-aged persons that included a variety of activities, were reciprocal in nature, and occurred outside of pre-arranged settings". Brewin, Renwick, and Schormans (2008) found that many activities that children with AS enjoyed were frequently not provided at school. This study concluded that "being excluded from physically active or sports-related activities was an obstacle to their child's ability to interact socially" (p247), i.e., activities tended to be tailored to the interests of the majority or from an ableist perspective.

Salmon (2013) researched how teenagers with disabilities maintained friendships and found that relations with the PNT were "fraught with tension due to ableism" (p351) and how they "had to resist prevailing norms about friendship" (p352). From my perspective, viewing the meaning of friendship of persons with autism in ableist terms may, therefore, have resulted in confusing

a deficit in PNT social skills with a lack of interest in socialising and resulted in difficulties making friends and maintaining friendships. This confusion may not have been a conscious undertaking. Instead, it may have resulted from the internalisation of normalcy and ableism by the PNT and persons with autism as explored in the next section.

2.12 Internalised normalcy and ableism

The role of internalised normalcy and ableism, the unconsciously held belief that casts disability as a diminished state of being, may have perpetuated the PNT dominant discourse of sociality and friendship that I now examine.

Campbell (2009) contended that internalised ableism is concerned with distancing persons with disabilities from each other, or dispersal and their adoption or emulation of ableist norms. The strategy of dispersal reflects the belief that less attention is drawn to individuals with disabilities than groups and results in a “dilution of deviancy” (Campbell, 2009, p23). This author described the strategy of emulating the norm as “defensive Othering” (2009, p24). Emulating the norm implies acceptance of their devalued identity whilst asserting that this doesn’t apply to them, but to other persons with disabilities.

As argued by Goodley ableism is internalised, so that (2014, p32) “Ableism is part of our un/conscious everyday lives”. Bauminger, Shulman, and Agam (2004) examined the perception of friendship in high-functioning children with autism and the link between perceptions of self, and of social relations between them. The findings were indicative of internalised ableism, i.e., despite children with autism perceiving their friendships to be as close as the PNT, they still regarded their social competencies to be inferior to and themselves less socially able than their PNT peers. Regardless of a comparable experience of friendship to the PNT, for me, the children with autism in this study had an unconscious belief that their social skills were indicative of the ‘Inferior Other’.

Explanations for the misconception that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills may,

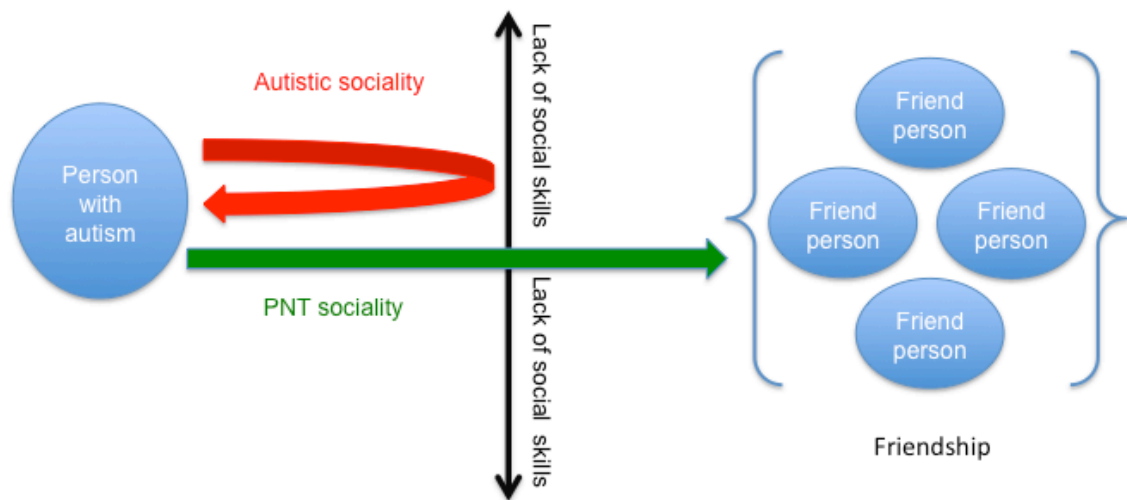
therefore, lie in the concept of internalised normalcy and ableism. The PNT corporeal standard of normalcy and its attainment is, for me, ubiquitous; it doesn't require acknowledgement or understanding. It exists and is communicated unknowingly and without question throughout society as embodying the only form of the human. O'Dell et. al., (2016, p168) stated, "The assumption of a non-autistic 'norm' is, in conventional understandings, unquestioned and naturalised". These authors called for society's assumption of a PNT perspective as our reference point to be opened to debate. As stated by these authors, what is required is "a different way of understanding autism that values the abilities of people with autism" (2016, p166).

To conclude, normalcy and ableism from the perspective of many academics and as I have outlined in relation to my perspective, may have contributed to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). Furthermore, for me, normalcy and ableism are the disabling concepts or social barriers that persons with autism encounter in the meaning they describe of sociality and friendship. I now present a summary of my literature review that explains my theoretical position and my subsequent interpretation of the key concepts that I have examined.

2.13 Summary

As shown in Figure One, the dominant discourse in the academic literature is that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (Orsmond, Wyngaarden-Krauss, and Seltzer, 2004; Bauminger, Solomon, and Rogers, 2010; Daniel and Billingsley, 2010; Locke et. al., 2010; Solomon, Bauminger, and Rogers, 2011; Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014):

Figure One



Sociality pathways and social barriers to making friends and maintaining friendships for persons with autism as described in the published literature

My review of the literature found that despite the sociality of persons with autism the positive experience of friendship that they desire and enjoy is often difficult for them to achieve. I argue that this conundrum has arisen from the binary of autistic and PNT sociality as illustrated by the two different sociality pathways in Figure One. For me, the PNT sociality pathway allows friends to be made and friendships to be maintained. In comparison, the autistic sociality pathway is positioned as other, lacking social skills and, therefore, encounters disabling social barriers that prevent persons with autism from doing so.

In defining my theoretical position, my aim is for the outcome of my research to contribute to resolving this conundrum. To do so, my theoretical position presents possibilities for an enabling narrative of sociality and friendship for persons with autism that: 1) deconstructs the binary of autistic and PNT sociality, and, therefore, advances a challenge to this dominant discourse on sociality and friendship; and 2) argues for a range of sociality and friendship possibilities across being human. To do so, I posit, I need to describe in my research the meaning of sociality and friendship of persons with autism from their perspective.

This chapter has presented a synthesis of the published literature relevant to understanding the research that has been undertaken on autism, sociality, and friendship. In particular I have defined my theoretical position and used this as a lens to interpret key concepts of relevance to my research. I now turn my attention to in Chapter Three identifying my philosophical and methodological framework.

3 Chapter Three: Philosophical & methodological framework

3.1 Introduction

In Chapter Two, I presented my review of the published literature relevant to understanding the research that has been completed on autism, sociality, and friendship. My theoretical position that I defined my literature review and my interpretation of the key concepts of relevance to my research, for me, present possibilities for an enabling narrative of sociality and friendship of persons with autism. Furthermore, I concluded that this narrative could only be achieved by researching the perspective of persons with autism. My philosophical and methodological framework must, therefore, align with my theoretical position.

In this chapter, I describe my rationale for my choice of methodology and methods in the context of my researcher positionality. In doing so, I reflect on the philosophical assumptions that I have made and my theoretical position. Chapter Three also examines ethical issues, summarises the sources used and describes the process of data collection and analysis undertaken. I also consider the academic uncertainties of my methodological choices. This allows me to acknowledge and account for inconsistencies that may have arisen in my research and to reshape my methodology accordingly. Opie (2004, p18) writes, “Usually, the most significant factor that influences choice and use of methodology and procedures is, ‘where the researcher is coming from’”. I begin then by presenting a synopsis of my researcher positionality.

3.2 Researcher positionality

The importance of researcher positionality was a subject of frequent academic discourse in the literature (Opie, 2004; Guba and Lincoln, 2005; Lucas, 2005, Reay, 2010). Denzin stated (1986, p12), “Interpretive research begins and ends with the biography and self of the researcher”. In justifying the rationale for my research strategy, defining my perspective as a researcher was of critical importance.

My researcher positionality is, therefore, a product of my prior knowledge, life experience, and environment and mine has been influenced by several factors. These include: 1) the academic research I have completed; 2) my lived experience as the mother and a parent-researcher; and 3) being a researcher without a disability researching a disability²². I now consider how each of these factors that have implications for my philosophical and methodological choices have shaped and informed my researcher positionality.

3.2.1 Academic research

The academic research I have undertaken is confined to my Masters degree and my work in the High Achiever's autism research project²³. My professional background is as a scientist. In contrast, the professional experience of many academics researching the lived experience of persons with autism is rooted in the domains of education or disability studies (Bagatell, 2010; Baggs, 2013; Bertilsdotter Rosqvist, Brownlow, and O'Dell, 2013; Martin, 2015). In addition, as I examine in section 3.5.2, many of these authors that have researched autism, sociality, and friendship from the theoretical position that I support have employed a qualitative methodology.

To research my focus of enquiry required me to move from a quantitative to a qualitative methodology (as I explore in section 3.5.1). This change to my researcher positionality commenced with my MA degree in the education of children and young people with autism, that I completed in 2006, and required me to choose my methodology solely on the nature of my focus of enquiry (Clark, 1998). Like other researchers who have made this journey in doing so, I have developed a greater understanding and a broader perspective of qualitative research (Hagger and Chatzisarantis, 2011). In particular, like these authors, I have developed my "recognition of the value of qualitative research

²² In examining my researcher positionality, I am using the term disability to reflect how this label is used in the literature on this subject. My theoretical position is as stated in Chapter Two.

²³ I'm a founder member of the High Achiever's research project that is investigating current approaches to supporting students with autism at universities in the UK. Our first manuscript has been published in the Journal of Higher and Further Education (Chown, et. al., 2017).

and its propensity to make a valuable contribution to knowledge and understanding of behaviour and outcomes” (Hagger and Chatzisarantis, 2011, p268). As stated by Chamak, et. al., (2008), in doing qualitative research I’m aiming to describe the complex and varied meaning of the sociality and friendship experiences of persons with autism from their perspective and, therefore, align my methodological framework with my theoretical position.

3.2.2 The parent-researcher

My lived experience of persons with autism is primarily as the mother of a son with the label of AS. As stated in Chapter One, I have always thought my son had social skills and desired to socialise, have friends, and friendships. My son has communicated the meaning that he described from these phenomena to me on many occasions. My role as a mother who is also a researcher, therefore, positions me within the parent-research paradigm (Carpenter, 1997; Kabuto, 2008 and 2010). As stated by Carpenter (1997, p396) the parent research paradigm “bestows the role of researcher on the parent”. Although parent-research has history, the academic community has given limited attention to this paradigm. Nevertheless, parent-research is regarded as a legitimate research paradigm (Carpenter 1997).

Parent-researchers have some unique advantages in comparison to professional researchers including: 1) access to an environment that may not be readily accessible to other professional researchers; 2) the ability to offer an intimate perspective on how their child or children experience phenomena and learn in the home environment; and 3) research that results in the empowerment of care giving (McCammon, Spencer, and Friesen, 2008). As stated by Carpenter (1997), parents are “the natural enquirer within their family, the seeker of knowledge and information that will illuminate needs within their family and specifically in relation to their child with a disability” (Carpenter, 1997, p396). This author argued the need to recognise the rights of parents to research issues of importance to their families.

Research has also concluded that in comparison to professional researchers parent-researchers formulated more meaningful research questions and collected better quality data (McCammon, Spencer, and Friesen, 2001; Chamak et. al., 2008; Guinchat et. al., 2012). Gillespie-Lynch et. al., (2017, p11) concluded that involving close family members in research may contribute to realising a better understanding of autism. Of particular relevance to my researcher positionality is the work of L'Esperance and Orsini (2016). These authors claimed that mothers and intended mothers, in the context of infertility and autism, seek to disrupt medical conceptualisations of these conditions and:

mobilise knowledge that lies at the intersection of medical expertise and social experience. They engage with and vigorously challenge medical expertise in order to have their experiences recognised as socially legitimate and medically relevant (L'Esperance and Orsini, 2016, p327).

I acknowledge, however, that the parent-research paradigm has been subject to criticism. Kabuto (2008; 2010) referred to the ambiguity that is attached to this paradigm due to its' lack of a clear definition. In addition, parent-researchers such as myself have a strong emotional connection with their research. As a result, we have been criticised for bias, or failing to maintain a suitable critical distance or a level of detachment and objectivity and overlooking discrepancies in or making pre-conceptions about our research (Liu and Vadeboncoeur, 2010; Kim and Kim, 2017).

Jenson (2008) a parent-researcher writes that objectivity in research is regarded as the 'gold standard' and the only knowledge of worth. However, the academic community is now beginning to question this assumption with Jensen (2008, p384) arguing, "The researcher's self, far from being an unwelcome intrusion into the production of knowledge to be kept silent, is foundational to knowledge itself". Other authors have also challenged this academic convention (Code, 1995; Carpenter, 1997; McCammon, Spencer, and Friesen, 2001). I argue that what is required in parent-research is the recognition that the roles of "parent" and "researcher" need to coalesce to capture the complexity of "their focus of enquiry" (Kabuto, 2010, p134).

Ensuring that the design and conduct of my enquiry resulted in findings that were trustworthy I regarded as being of prime importance to me (Lincoln and Guba, 1985)²⁴. In my study, I tried to be aware of how I was viewing and listening to my sources to allow me to recognise and reflect on my bias, an issue that I will return to later in my thesis. My aim was to describe only the meaning of sociality and friendship of the sources. Similarly to Jensen (2008) however, I also regarded my emotional connection to my research as an asset that was foundational to the knowledge I created. In doing so, as stated by Davidson and Orsini (2010, p132), I must as a parent-researcher in reflecting my theoretical position “continually question experience and expression of emotion in all senses and spaces, including, and perhaps, especially, what counts as ‘normal’ in mainstream society”.

3.2.3 Role as a non-disabled researcher in researching autism

I’m a researcher without a disability researching disability. In the academic community this relationship has been the subject of extensive academic discourse (Barnes, 1992 and 1996; Barnes and Mercer, 1997; Humphrey 2000; Allen 2005; Martin, 2015; Puyalto et. al., 2015). Research has highlighted the ambiguity of this position (Barnes, 1992 and 1996; Barnes and Mercer, 1997; Humphrey, 2000). On one hand, authors claimed that persons with disabilities have invited non-disabled researchers to undertake research that may empower persons with disabilities claiming it isn’t necessary to have an impairment to do so (Barnes, 1992). Conversely, the same author acknowledged that a researcher could only empathise with a participant if they have had very similar life experiences and, therefore, their research may lack authenticity (Barnes, 1996; Allen 2005). Humphrey (2010, p76) a non-disabled researcher in disability research writes that “At one extreme, I was welcomed to the point of being treated and even named as an ‘honorary disabled member’ and “At the other extreme, I was cast as an outsider-cum-oppressor”.

²⁴ I use the term ‘trustworthy’ in the context of the meaning of Lincoln and Guba (1985), i.e., that to evaluate the worth of research trustworthiness is important. Any reference to trustworthy in this context is always followed by a reference to the authors, Lincoln and Guba (1985).

Martin (2015) a non-disabled researcher working with persons with AS, acknowledged that she couldn't possess the expertise of the participants in her study. However, she remained committed to designing research with the participants "in a way that transformed the 'social relations of research production'" (Martin, 2015, p210). Rather than focusing on whether the researcher was a disabled or a non-disabled person, other authors have claimed that what persons with disabilities needed was: 1) research to be useful and relevant to them (Barton, 2005); 2) to be aimed at improving the lives of disabled persons (Martin 2015); and 3) that non-disabled researchers should be on the side of persons with disabilities (Johnson, 2009).

3.2.4 Role as a non-disabled mother of a child with autism

As I have explored in sections 3.2.1 and 3.2.2, there are ambiguities for me as a parent-researcher and as a non-disabled researcher researching disability. In addition, I am a mother without a disability who has a child with autism. Ryan and Runswick-Cole (2008) explored how non-disabled mothers, like me, are portrayed in the disability studies and the wider published literature. These authors concluded that although often marginalised and undervalued, mothers are able to realise change and were characterised as being their child's ally. Ryan and Runswick-Cole further argued, "The mothers of disabled children are more than allies to their disabled children, as they experience directly and by proxy many of the discriminatory practices and attitudes that their disabled children face" (2008, p202). These authors also claimed that mothers of children with disabilities develop a special competence championing the rights of their children, and, by adopting this crusader orientation, work to achieve change. Other research has also highlighted the essential role that parents, mainly mothers, play in securing support for their child with a disability (Ryan and Runswick-Cole, 2009; Brennan et. al., 2016).

Chamak and Bonniau (2013) researched how parents of children with autism have experienced the diagnostic process in France over the last twenty years. Prior to the 1990's, parental anxiety, concerning their child's behaviour, was initially dismissed by professionals as being unfounded or being attributed to

poor parenting that later led to a diagnosis of autism. Since this date, improvements in diagnostic practice occurred with parental associations having played a key role in this process. Parents became crusaders in changing the understanding of autism in French society as they “fought against the judgment of bad parenting and the definition of autism as a psychiatric disease” (Chamak and Bonniau, 2013, p420). These authors concluded that the activism of the parents of children with autism in France had “succeeded in reshaping beliefs and practices in diagnosis, etiology, and treatment of autism” (Chamak and Bonniau, 2013, p421). Similarly, Ryan and Runswick-Cole (2009) found that most mothers of children with autism joined support groups to enable them to campaign for change for their children by lobbying government officials and raising awareness of autism in society.

Hodge and Runswick-Cole (2008) found that parents of children with autism felt disempowered by professionals and that their knowledge of their child was regarded in comparison as lesser and inferior. This positioning of parental knowledge has resulted, in some instances, in parents developing a comparable level of professional knowledge. These authors concluded, “it is the professionals who are willing to learn about the child, rather than those who only want to know about the ‘disability’, who are able to work effectively as partners” (Hodge and Runswick-Cole, 2008, p645). Similarly, Wilhelmsen and Nilsen (2015) found a failure of professionals to recognise parental knowledge when assessing children for potential special educational needs. There was, therefore, a need during this process to “take account of the familial knowledge base and parents’ experiences” (Wilhelmsen and Nilsen, 2015, p251) a conclusion also reached by other authors (Ho et. al., 2014).

In contrast, Ryan and Runswick-Cole (2008) also explored the characterisation of non-disabled mothers as the oppressor of their child with disabilities. Issues described by these authors included their wish to normalise and silence their child and their inability to view their child positively. Research has also found that parents of children with autism may have a different and contradictory understanding of autism compared to their children. Bertilsdotter Rosqvist, Brownlow, and O’Dell (2014) researched the tensions between advocacy, or

parent-led, and self-advocacy autistic movements in Sweden. The parental discourse positioned autism as “problematic and ascribe to a deficit-focused view of autism” (Bertilsson Rosqvist, Brownlow, and O’Dell, 2014, p220). In contrast, the self-advocacy discourse, or that of persons with autism, was found to value autism as a form of neurodiversity focusing on its’ strengths and possibilities. These authors concluded that whilst parents and persons with autism in advocacy movements share similar objectives, their positions are divided and that this “reflects the perceived secondary position of the self-advocate narrative within the wider discourse of autism advocacy movements” (Bertilsson Rosqvist, Brownlow, and O’Dell, 2014, p230). This divided position may result in tensions as to how to empower persons with autism, i.e., advocacy movements that involve parents preferring to gain influence through working together whereas self-advocates wanting to work alone with a focus on achieving power.

Orsini and Davidson (2013) wrote that the understanding of autism is shaped by various and at times contradictory discourses of academics, persons with autism, and their carers including parents. These authors stated that parents have been at the forefront of constructing understandings of autism with a focus on caring and treatment. In contrast, persons with autism often reject any form of treatment preferring to adopt the perspective of neurodiversity²⁵. Ryan and Runswick-Cole (2009, p46) wrote that “mothers’ disability activism also has an impact ‘for good or ill’ on their children”. The children with autism in their research used contradictory phrases to describe their parents such as, “fought for me, giving me opportunities, not wanted and never allowed” (Ryan and Runswick-Cole, 2009, p46).

I acknowledge there is ambiguity in the efficacy of a non-disabled researcher such as myself, who is also the mother of a child with autism, in conducting disability research and that this issue may, therefore, be the subject of continuing academic debate. In particular as a PNT person, I lack an understanding of the person with autism’s meaning of sociality and friendship.

²⁵ As I explored in section 2.4.1, the neurodiversity movement supports my theoretical position regarding autism as a natural variation of the human (Jaarsma and Welin, 2011).

However, whilst acknowledging this as a limitation of my study, I wanted to understand more about how persons with autism experience these phenomena from their perspective and this is the purpose of my research. Despite this limitation, my theoretical position, an enabling narrative of autism aligns with the perspective of other authors who as non-disabled researchers have researched disability, e.g., Humphrey (2010) and in-particular autism, e.g., Martin (2015).

In addition to the factors that I have examined, methodological choices are also informed by the philosophical assumptions of academic enquiry (Guba and Lincoln, 2005; Lucas, 2005). I now describe my position in relation to these philosophical assumptions that have been influenced and shaped by my researcher positionality and my understanding of autism.

3.3 Philosophical assumptions

3.3.1 Epistemological position

Epistemology can be defined as the nature of knowledge, including its acquisition and communication to others (Opie, 2004). To describe my epistemological position I needed to reflect on my understanding of autism. My theoretical position posits that each person with autism is a unique individual whose lived experience is exclusive to them and varies over time. I believe it's from the lived experience of persons that knowledge originates it being a product of their thoughts and feelings. I hold that individuals are able to instigate actions and make their own decisions and that it's by these means that they experience the world.

I believe that sources are reliable reporters of their own experience and that by listening to their accounts I can inform knowledge. The pursuit of knowledge, for me, involves listening to people, is a subjective experience, and a social construct. This doesn't mean to say that individuals may or should be expected to remember everything accurately or with perfect clarity. Levering wrote (2006, p462), "The question whether the experience is true or not is unhelpful. We do not ask whether stories are true or untrue, but whether they are convincing or

unconvincing”. My epistemological position is that knowledge arises from the reflection on and communication of the lived experience of persons with autism from their perspective. My epistemological position, therefore, aligns with my theoretical position, i.e., presents possibilities for an enabling narrative of sociality and friendship of persons with autism.

3.3.2 Ontological position

Ontology is the nature or essence of being (Opie, 2004). My ontological position is that there are many different versions of reality and an individual’s is unique and strongly influenced by social positioning. For persons with autism a social oppression theory of disability (Oliver, 2006) reflects my interpretation of the nature of being. As I stated in Chapter Two, the social model of disability (Oliver, 2006) posits impairment and disablement as separate entities (Tregaskis, 2002). The social model of disability that is integral to my theoretical position acknowledges the frequently disadvantaged outcome of persons with autism in a PNT dominated society (Beardon, 2017). Thomas writes (2004, p33):

Disability now resided in a nexus of social relationships connecting those socially identified as impaired and those deemed non-impaired or ‘normal’, relationships that worked to exclude and disadvantage the former while promoting the relative inclusion and privileging of the latter.

I claim, therefore, that persons with autism are only disabled by the attitudes of society towards them, and the environmental factors that these inform, resulting in the social barriers that they experience. In accordance with the principles of the social model of disability, for me, it is the responsibility of society to change and adapt to allow persons with autism to live the life they want to lead (Oliver, 1983). To facilitate this change my ontological position, a social oppression theory of disability, aligns with my understanding of autism that presents possibilities for an enabling narrative of sociality and friendship for persons with autism.

3.3.3 Axiological position

Axiology is the philosophical study of values that is rooted in the concept of ethics (Hiles, 2008). In terms of my researcher positionality, I needed to reflect on how I defined ethical theory and practice. My ethical position is based on the underlying principles of respect, beneficence, non-maleficence, and justice (Bishop, 2009). I believe that persons have the right of choice, to hold views, and to take actions based on their own principles and beliefs. My research must treat everyone fairly, primarily be of benefit to persons, and mustn't intentionally result in harm²⁶. My axiological position is also embedded within my ontological position, a social oppression theory of disability and, therefore, aligns with my understanding of autism²⁷.

Having presented a synopsis of my researcher positionality and described my philosophical position I now describe the rationale for my methodological framework.

3.4 Methodological framework

I needed to select a methodological framework that allowed me to answer my research questions. To achieve this aim my choice of methodology needed to: 1) align with my theoretical position; and 2) reflect my researcher positionality and the philosophical assumptions that I had made. In doing so, as described by Mertens (2007, p215) "I have choices to make that go beyond quantitative, qualitative, or mixed methods, to how I collect data about the reality of human experiences in such a way that I can feel confident that I have indeed captured that reality".

The next section of Chapter Three provides the justification for my methodological framework. Research frameworks or paradigms are derived from a belief system and guide how researchers undertake an enquiry. Morgan

²⁶ Which is also a requirement of SHU's ethics policy.

²⁷ In section 3.7, having outlined my methodological position and choice of methods I examine the ethical implications of my research in more detail.

wrote (2009, p50) paradigms are “worldviews or all-encompassing ways of experiencing and thinking about the world, including beliefs about morals, values and aesthetics”. My choice of research paradigm was, therefore, critical in determining how I was to undertake my research. In the next section, I present my rationale for my choice of research paradigm.

3.4.1 Research paradigms

Mackenzie and Knipe stated (2006, p193), “It is the choice of paradigm that sets down the intent, motivation, and expectations for the research”. Similarly, Morgan claimed paradigms (2009, p49) “influence how researchers select both the questions they study and methods that they use to study them”. The selection of an appropriate paradigm was, therefore, my critical next step in providing a sound basis for my subsequent choice of methodology and methods enabling me to conduct meaningful research.

The principle paradigms of educational research have been the subject of extensive academic discourse (Guba and Lincoln, 1994; Somekh and Lewin, 2005; Cohen, Manion, and Morrison, 2004). Mertens (2010) identified four generally recognised key paradigms, positivism, constructivism (interpretivism), pragmatism, and transformativism. Each paradigm has evolved over time and has its own understanding of axiology, ontology, epistemology, theories, methodologies, and methods. I critically appraised all four paradigms²⁸ and concluded that transformativism would allow me to answer my research questions. I now present a detailed examination of this paradigm as to its suitability to researching the meaning of sociality and friendship for persons with autism from their perspective.

3.4.2 Transformativism

The transformative paradigm is a new concept that was developed during the 1980s and 1990s (Mackenzie and Knipe, 2006). As described by these authors,

²⁸ In addition to transformativism, I critically analysed positivism, constructionism, and pragmatism. However, I haven’t included the results of this examination in my thesis.

transformativism emerged as a reaction to the non-inclusion of minority groups in educational research or persons who don't hold the majority of social power in society. This included persons with disabilities, migrant populations, faith groups, and gender or sexual minorities. Transformative researchers "believe that inquiry needs to be intertwined with politics and a political agenda" (Creswell, 2009, p9). Key ethical issues include respect for different cultures, promotion of human rights, and social justice (Mackenzie and Knipe, 2006; Mertens, 2010). The transformative paradigm recognises there are different versions of reality and that an individual is based on social positioning.

Transformative research utilises a qualitative or mixed methodology that provides "more complete and full portraits of our social world through the use of multiple perspectives and lenses" (Greene, Kreider, and Mayer, 2005, p275). This paradigm includes contextual and historical factors, with reference to the marginalisation or oppression of the individual or group being studied (MacKenzie and Knipe, 2006). A diverse range of research tools is used to avoid discrimination against, or oppression of, participants. The transformative paradigm, therefore, aligned with my epistemological, ontological, and axiological positions, and my researcher positionality and theoretical position.

Embedded within each major paradigm are specific conceptual frameworks with key features that distinguish them from others in the same group (Mackenzie and Knipe, 2006). The transformative paradigm includes emancipatory research that can be defined as research that aims to empower the subjects of social enquiry (Letherby and Jupp, 2006). In the early 1990s, Oliver (1992) proposed a paradigm shift to this new set of beliefs, the emancipatory paradigm for disability research.

3.4.3 Emancipatory disability research

The oppression of persons with disabilities has been endemic in educational research (Oliver, 1983 and 1992; Barnes, 2003; Campbell, 2009; Hodge and Runswick-Cole, 2013; Goodley, 2014; Milton 2014). Disability research has historically been embedded in the positivist paradigm and was preoccupied with determining the incidence of disability in society (Danieli and Woodmans,

2007). Implicit in the positivist paradigm was the hierarchical relationship between the typical PNT researcher and research subject with disabilities, and the resultant power differential between them. Research has traditionally emphasised and highlighted the differences between the PNT and persons with disabilities whilst failing to acknowledge their frequent disadvantaged outcomes (Beardon, 2017).

Oliver said, "Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life" (Oliver, 1992, p105). Oliver first proposed the development of an emancipatory research paradigm for researching disability. In contrast to traditional approaches, this paradigm embraced the social model of disability that locates disability within the social environment rather than the individual. Emancipatory disability research is, therefore, "about the empowerment of disabled people through the transformation of the material and social relations of research production" (Barnes, 2003, p6).

Based on my appraisal, emancipatory disability research with its foundations in the disability movement would allow me to answer my research questions and presents possibilities for an enabling narrative of sociality and friendship for persons with autism. Stone and Priestley (1996, p706) provided a summary of the requirements of emancipatory research as follows:

- Adoption of the social model of disability
- Surrender of claims to objectivity
- Must have practical benefits for persons with disabilities or contribute to barrier removal
- Devolution of control to persons with disabilities over research
- Providing a voice to persons with disabilities

- The flexibility of methods of data collection and analysis to meet the needs of participants with disabilities.

The values of this paradigm are empowerment and reciprocity (French and Swain, 1997). As defined by these authors, “Empowerment is a process whereby people are enabled to take control of their lives” (p28). Reciprocity in research can be defined as “an ongoing process of exchange with the aim of establishing and maintaining equality between parties” (Martin, 2015, p220). In his conceptualisation of the social model of disability, Oliver (1992) added a third principle of gain that requires persons with disabilities to perceive the research as being of benefit to them (Martin, 2015).

Emancipatory disability research has been the subject of extensive academic discourse (French and Swain, 1997; Barnes, 2003; Sullivan, 2009; Martin, 2015). As with the social model of disability (see section 2.4), this research paradigm has also been subject to similar criticisms. However, I concluded that emancipatory disability research would allow me to answer my research questions as it: 1) aligned with my theoretical position; and 2) reflected my researcher positionality and the philosophical assumptions that I had made. I, therefore, chose to position my focus of enquiry with this paradigm.

The next issue I wished to explore was my choice of methodology and methods. My selection needed to enable me to effectively research the meaning of sociality and friendship for persons with autism from their perspective, and align with my choice of research paradigm. This is the subject of the next two sections of this chapter.

3.5 Methodology

Distinct from paradigms are methodologies that can be defined as the “principles, theories and values that underpin a particular piece of research” (Somekh and Lewin, 2005, p347). I now present my critique of the aims, strengths, and weaknesses of my chosen approach of a qualitative methodology.

3.5.1 Qualitative methodology

I believe that knowledge is a social construct and originates from the thoughts and feelings of individuals. Numerous authors have critiqued qualitative research and concluded that this approach investigates, in depth, how people think and feel (Cohen, Manion, and Morrison, 2004; Opie, 2004; McLeod, 2008). Qualitative research consists of several approaches that can be used to address questions about a particular interest, reflecting the positionality of the researcher. The aim is to describe meanings and how they are understood, together with patterns of human behaviour (Pope and Mays, 1995).

Qualitative methodologies have several strengths and weaknesses such as the flexibility to explore different perceptions and meanings of a phenomenon (Opie, 2004; Creswell, 2009; Mertens, 2010)²⁹. Strengths described by these authors included the ability to examine issues in detail and in depth, presenting rich data that is both subtle and complex. Other advantages include the responsive nature of the research strategy to change that allows it to be restructured as new data emerges. A specific advantage with respect to my focus of enquiry was that qualitative research is suited to studying a small number of individuals in depth, in naturalistic settings, and lends itself to exploring how and why a phenomenon occurs (Pope and Mays, 1995).

Authors in the literature also described the limitations and weaknesses of qualitative research (Opie, 2004; Creswell, 2009; Mertens, 2010). These include the presence, competency, and personal biases of the researcher that can significantly influence the quality and direction of the research³⁰. The quantity of data produced can be large and difficult to manage, making analysis and interpretation time consuming. Difficulties in managing the dataset may bring into question the rigour of the research that is influenced by the competence of the researcher. More importantly, as generalisation isn't the aim

²⁹ I acknowledge that quantitative methodologies also have strengths and weaknesses. As this approach to research didn't align with my researcher positionality I haven't considered the merits and demerits of quantitative methodologies in my thesis.

³⁰ The academic tension presented by my emotional connection to my research that may have resulted in bias is an issue I return to examine later in my thesis.

of qualitative research, results cannot be applied to a larger population (Pope and Mays, 1995).

3.5.2 Researching disability

As described in Chapter Two, historically, disability research has been driven by criticisms of the medical model of disability and its preoccupation with defining the incidence of disability in society (Danieli and Woodhams, 2005; Mallet and Runswick-Cole, 2014). Such research used quantitative methodologies and didn't contribute to the removal of social barriers (Stone and Priestley, 1996; Danieli and Woodhams, 2005).

These criticisms resulted in a move by some researchers to use qualitative methodologies to research the thoughts and feelings of individuals and to challenge social oppression. Stone and Priestley (1996) claimed that research that is emancipatory in nature is often thought to be synonymous with a qualitative approach. Other authors have also found support from the disabled community for the use of qualitative methodologies. Kitchin (2000) found participants favoured qualitative methodologies as they enabled them to express their beliefs and opinions³¹.

I appraised the authors cited in my literature review who had researched the phenomena of sociality and friendship for persons with autism. All authors used a qualitative approach (e.g., Carrington, Templeton, and Papinczak, 2003; Chamberlain, Kasari, and Rotheram-Fuller, 2007; Davidson and Smith, 2009; Daniel and Billingsley, 2010; Moyson and Roeyers, 2011; Martin, 2015). My concern was to select an approach that maximised the strengths and minimised the weaknesses of the methodology, and was suitable for researching the meaning of sociality and friendship for persons with autism from their perspective. Whilst I acknowledge and recognise the academic uncertainties of different approaches, I decided, based on my understanding of methodology

³¹ I acknowledge that other authors have argued that emancipatory disability research can utilise quantitative or a plurality of methodologies (Miller and Gwynee, 1972; French and Swain, 1997; Vulliamy and Web, 1995; Barnes and Sheldon, 2007).

presented in this chapter, to select a qualitative approach to my enquiry that would allow me to answer my research questions as it: 1) aligned with my theoretical position; and 2) reflected my researcher positionality and the philosophical assumptions that I had made. The next issue I needed to address was my choice of research methods. In section 3.6, I present the rationale for my choice.

3.6 Methods

Methods are the tools that are used to collect and analyse data (Opie, 2004). In deciding on the appropriate methods that would allow me to describe the meaning of sociality and friendship for persons with autism from their perspective, I begin by examining the position and lived experience of persons with disabilities including autism in research. In examining and defining my methods, I'm once again using the term disability to reflect how this label is used in the literature on this subject.

Persons with disabilities are one of the most over-researched minority groups in western society and may experience research fatigue (Clark, 2008). The repeated demands on a minority group to participate in research projects has resulted in individuals disengaging from the process, no longer valuing its outcome, and in extreme instances withdrawing from projects (Clark, 2008). Other authors have also documented research fatigue of persons with disabilities (Kitchin, 2000; Iacano, 2006; Milton, 2014). I was, therefore, conscious of the need to choose research methods that didn't impose any further demands on persons with autism to participate in research.

The main methods of data collection in qualitative research include interviews, focus groups, questionnaires, descriptive accounts, and observations (Opie, 2004). In not wanting to impose participatory research demands on persons with autism, I didn't consider interviews, focus groups, questionnaires, or observations, all techniques that require interaction between the researcher and the researched. Descriptive narratives in the form of autobiographical accounts in the public domain are open to critique and review and don't require the

participation of persons with autism. As a result of my researcher positionality, theoretical position, and philosophical assumptions I'm drawn to a particular sort of data that allows persons with autism to describe their meaning of sociality and friendship in their own words, i.e., narrative accounts. In the following sections, I present my rationale for my choice of a particular form of narrative that of autobiographical accounts and critically appraise their advantages and limitations.

3.6.1 Autobiography as a data source

Hopkinson and Hogarth-Scott (2001) described how stories can be conceptualised in a three level hierarchy. At the top of the pyramid are myths or universal truths, in the centre are stories or narratives, and below are accounts of actual facts and events. These authors claimed that (2001, p28) "Like myth, 'narratives' is not true to external reality, but narrative is distinctive in that it is the means through which the teller imposes an order upon what they see, thereby constructing reality and creating their understanding of events".

Autobiographies are the narratives of a person's life or a significant, defining period of time or experience, and can result in new understandings of a phenomenon. Autobiographical accounts allow the person to describe their experience of a phenomenon from their perspective and in their own words, emphasising the most meaningful aspects of their lived experience (Power et. al., 2012). Autobiography is a:

form of social communication that requires self awareness, projection, imagination, organisation and reconstruction, as well as the ability not only to recognise others, but also to wish to communicate and interact with others (Rose, 2008, p46).

It is this definition of autobiography that I have adopted for the context of my research. My choice of autobiographical accounts as my data source may have advantages in comparison to other data sources. Advantages include being unsolicited and less influenced by the disposition and attitudes of the researcher (Power, et. al., 2012). Using autobiographical accounts as a data

source may, therefore, allow me to maintain a critical distance from my research and recognise and reflect on my bias.

The need to avoid bias and maintain a critical distance in research has been the subject of academic debate. Olesen (1994) and Hayes (2006) argued for the futility of trying to avoid subjectivity in autobiographical research and regarded 'bias' as a useful resource. Hayes (2006) reflected on her role as the researcher and stated, "I reject the notion of bias, therefore, and embrace subjectivity as a means of understanding human lived experience and the physical, political, and historical context of that experience" (p404).

I acknowledge that my researcher positionality presented me with an academic tension in the need to avoid bias in my research for my findings to be regarded as trustworthy (Lincoln and Guba, 1985). To do so, I tried to be aware of how I was selecting and then viewing and listening to my sources to allow me to recognise, reflect and, therefore, avoid bias. However, similarly to Olesen (1994) and Hayes (2006) I regarded my researcher positionality as an asset in my choice of autobiographical accounts as a data source.

There are different sources of autobiographical narratives that may present researchers with differing perspectives and contexts of lived experience. These include written accounts published in books, posts of video blogs on social media, and interviews posted on Internet websites. In the following section, I present my rationale for my choice of autobiographical narrative environments that I used as data sources.

3.6.2 Autobiographical narrative environments

Autobiographical accounts provide a breadth and depth of knowledge of a person's lived experience, and present researchers with a unique and unparalleled research opportunity (Mathias and Smith, 2016). Van Manen (2016, p72) described the genre as, "rich ore of lived-experience descriptions". Autobiographical accounts have been used as a data source in researching the lived experience of persons with autism (Barrett, 2006; Chamak et. al., 2008; Rose, 2008; Davidson and Smith 2009; Ochs and Solomon, 2010; Bertilsdotter

Rosqvist, Brownlow, and Odell, 2013). In addition, authors with autism, such as Lawson (2001) and Williams (1992 and 1995), support the use of their writing to inform discussion (Barrett, 2006).

The objective of my research rationale was to capture the meaning of sociality and friendship of persons with autism from their perspective, as reflected in different autobiographical environments. The use of diverse environments as data sources allows the person with autism to select their preferred mode of storytelling (Sunderland et. al., 2015). These authors claimed, “Multimedia narratives offer a sensorially and contextually rich way of communicating embodied and emplaced experience that offer story ‘listeners’ a chance to learn about and reflect upon *another’s life*” (author’s italics) (p51). Other authors who have researched autobiographical accounts claimed that persons with autism prefer written communication (Davidson and Henderson, 2010).

From my reading of the literature, it was essential for my choice of methods to align with my theoretical position, researcher positionality, and reflect the philosophical assumptions that I had made. I needed, therefore, to collect data from a diverse range of storytelling environments that would allow persons with autism to describe their meaning of sociality and friendship in their own words from their preferred storytelling environment. From my own personal experience, I knew that persons with autism used a number of popular forms of autobiographical environments, i.e., books, social media, and Internet websites. I now examine these in more detail, in terms of how they informed my choice of data sources including opportunities to recognise and reflect on my bias.

3.6.3 Published autobiographies

Persons with autism have been publishing accounts of their lived experiences in books since the mid-1980s (Baggs, 2013). As of 2008, there were in excess of fifty autobiographies in print (Rose, 2008³²). These autobiographical accounts

³² Whist an extensive search of the literature was undertaken, a more recent figure of the number of published autobiographies of persons with autism couldn’t be found. Internet searches found reference to many more autobiographies than Rose (2008) identified. As stated by Davidson and Smith

described all aspects of the lived experience of persons with autism, including sociality and friendship. Autobiographical narratives in books have also been used in researching the lived experience of persons with autism (O'Neill and Jones, 1997; Chamak et. al., 2008; Davidson and Smith, 2009; Elwin, et. al., 2012).

Autobiographies in books as a data source present several advantages and disadvantages to the researcher (Mathias and Smith, 2016). Books allow persons with autism to communicate their experiences and desires to society through the printed word. The author, the expert on how they experience a phenomenon, also provides a unique insight into their lived experience. Also, books provide an author with time to retrospectively reflect, engage, and change how they recall an experience to ensure its accuracy (Power et. al., 2012).

Conversely, having to recall events from memory of an experience that occurred long ago, can distort or omit details, and result in a narrative that is exaggerated or over-elaborated (Mathias and Smith, 2016). Other disadvantages are that authors want their books to sell, and may wish to present a certain image of themselves that influences how they remember and retell an experience. An author may be economical with the truth, sensationalise, or distort a description (Power et. al, 2012).

Davidson and Smith (2009) summarised the particular issues of using autobiographies of persons with autism in research, e.g., the reliability and interpretation of memories, the shaping of an author's perspective by other autobiographies, and the pressure to conform to society's current views of persons with autism. However, these authors concluded that, "such life narratives provide an invaluable yet underexplored qualitative resource for those interested in understanding 'insider accounts' of ASD" (2009, p902). As stated by Conn (2015), there is now increasing academic interest in using the autobiographies of persons with autism as a data source in academic research.

(2009), estimating the exact number of autobiographical accounts is difficult if not impossible.

3.6.4 Online environments

Online environments present academics with a new³³ material source of autobiographical narratives, and a challenge to traditional methodological practices in researching lived experience (Soukup, 2014). Brownlow, O'Dell, and Bertilsdotter Rosqvist argued (2013, p91), "The Internet and related technologies potentially provide a crucial tool in the living and sharing of experiences and understandings that would not have been possible previously". The Internet is now being used globally as a tool by researchers to provide instantaneous access to data sources (Harriman and Patel, 2014). As the Internet evolves it will continue to impact the process of academic research (Lee, Fielding, and Blank, 2008). In researching phenomena of interest, the Internet facilitates unrivalled online access to the lived experience of individuals and groups (Hine, 2011). Whilst online sources are a comparatively new research tool, their use is now an established practice. With regard to researching the lived experience of persons with autism, Davidson (2008c, p791) wrote, "The internet is shown to be an appropriate, accommodating medium for those on the spectrum, given characteristic preferences for communication at a socio-spatial distance".

Online environments include platforms such as YouTube, Facebook, and Twitter. Millions of social media users publish content every day that's in the public domain, everlasting, and searchable. There are several websites that describe the lived experience of persons with autism, and these include *Adultswithautism* (2015), *Ambitiousaboutautism* (2016), and *Healthtalk* (2016a). All three websites (and others) provide opportunities for persons with autism to describe their lived experience in their own words.

The use of social media content as data is increasing in academic research (Giglietto, Rossi, and Bennato, 2012; Lafferty and Manca, 2015). Lafferty and Manca (2015) categorised social media research as observational or interactive. These authors defined observational research as research "which

³³ The Internet was developed from the 1980s onwards with the World Wide Web opening to the public in 1991 (Internetsociety, 2016). YouTube was created in 2005 (Thomas, 2010).

does not require researchers to interact with human subjects to access and collect the data where SoMe³⁴ is open research data” (Lafferty and Manca, 2015 p90). Interactive research requires the researcher to interact with the person who posted on social media. Based on my examination of the literature, to align with my theoretical position and researcher positionality and to reflect the philosophical assumptions that I had made, I undertook observational research with open research data, as this didn’t impose demands on persons with autism to participate in my study.

3.6.5 Social media

Giglietto, Rossi, and Bennato (2012) critically appraised the characteristics of three social media platforms, YouTube, Twitter, and Facebook, that they claimed enjoyed huge popularity amongst users and researchers. These authors described YouTube as being “the most important video-sharing platform with 800 million users monthly, 4 billion videos viewed daily, and 60 hours of video uploaded every minute” (p147). Other advantages of YouTube that supported my researcher positionality and theoretical position, was the ability of video bloggers to present extended narratives that described their lived experience and for real-life data to be observed “without any interference from the researcher(s)” (Lafferty and Manca, 2015, p91).

The characteristics of Twitter and Facebook wouldn’t have allowed me to access data that was as rich as from YouTube. The focus of Twitter is microblogging³⁵, with up to 340 million posts or tweets posted per day, each limited to 140 characters (Giglietto, Rossi, and Bennato, 2012). Facebook was described as “the most popular social medium in the world” (Giglietto, Rossi, and Bennato 2012, p149), with more than 900 million active users. However, these authors stated that researchers have found a more limited use for Facebook data due to accessibility issues that result from the platform’s complex privacy settings. In addition, whilst Facebook has a multimedia

³⁴ Social media

³⁵ Microblogging can be defined as “a new form of communication in which users can describe their current status in short posts distributed by instant messages, mobile phones, email, or the web” (Java, et. al., 2007, p56).

approach, combining photographs, videos, and textural comments, with a limit of 63,206 characters in a status update, the optimum length of a text post is 40 characters (Kolowich, 2016). YouTube was, therefore, chosen as my social media data source, and I now critically appraise its use in academic research.

3.6.6 YouTube

YouTube created in 2005 (Thomas, 2010) is a form of self-presentation or expression (Griffith and Papacharissi, 2010), and “offers students, teachers, and practitioners of qualitative researchers a unique reservoir of video clips” (Chenail, 2011, p229). Prior to the creation of YouTube, the video had a long history of being used as a data source (Jewitt, 2012), including the lived experience of persons with autism (Barrett, 2006). This video hosting website was described as having enormous potential to generate and share data sources for use in research (Chenail, 2011), with YouTube video blogs already having been used to study a variety of interests (Soukup, 2014).

There are advantages of using YouTube video blogs as a data source. Giglietto, Rossi, and Bennato (2012, p151) stated YouTube video blogs present “a trace of social behaviour, a way for accessing meanings of a community”. In comparison to autobiographical accounts published in books, posting a video blog maybe a more spontaneous act, and this may result in less bias or fewer inaccuracies in a narrative account (Power et. al., 2012).

Brownlow, O'Dell, and Bertilsdotter Rosqvist (2013) in their research with persons with autism recognised YouTube as the primary site for the sharing of online videos in online social networking. They stated (2013, p90), “YouTube offers potential for many to broadcast their own ideas and concepts to a broad international audience”. For persons with autism, YouTube may be a particularly useful tool as it facilitates communication and may provide opportunities to make friends and maintain friendships without the need to share the same physical space (Brownlow, O'Dell, and Bertilsdotter Rosqvist, 2013). Online technologies such as YouTube “may allow autistic individuals to narrate the highs and lows of autism ‘from the inside’” (Davidson and Orsini,

2010, p132), and “provide safe spaces for autistic people to meet and interact with each other” (Bertilsson Rosqvist, Brownlow, and O’Dell, 2015, no page number).

There are limitations with using YouTube as a data source. YouTube video blogs weren’t created for the purposes of research but as a means of self-expression. In the last decade, YouTube video blogs have been ‘repurposed’ by the research community (Adami, 2010; Jewitt 2012). Researchers have, therefore, used available video blogs for a different purpose from that originally intended. Other limitations include that a person’s motivation to create and post a video blog isn’t known and, therefore, personal bias cannot be ruled out.

To use YouTube successfully as a data source, researchers need to gain an understanding of the technical and cultural context of this platform (Giglietto, Rossi, and Bennato, 2012). YouTube isn’t a search engine and this results in limited functionality in being able to identify and categorise material (Soukup, 2014). Sampling YouTube data can be challenging as distributions of video blogs are often determined by the activity rate of users. From the perspective of researching disability, traditional power relations may exist that privilege the status of video blogs posted by professionals over that of persons with autism (Brownlow, O’Dell, and Bertilsson Rosqvist, 2013). YouTube as concluded by these authors “offers the possibilities for shaping new understandings of autism, ones that are very much generated from the individuals who identify themselves with the label” (Brownlow, O’Dell, and Bertilsson Rosqvist, 2013, p92). Despite its criticisms, YouTube is considered in the literature to be a powerful tool and potentially a rich data source.

3.6.7 Websites

In choosing a website as a data source, I began by reviewing the websites available that contained autobiographical accounts of persons with autism. Several websites including Adultswithautism (2015), Ambitiousaboutautism (2016), and Healthtalk (2016a), contained videos or transcripts of interviews by persons with autism that described their lived experience. Only Healthtalk

(2016a) contained data specifically on sociality and friendship. As these phenomena were the focus of my enquiry, I chose Healthtalk as my website data source.

Healthtalk, created in 2001 (Kidd and Ziebland, 2016), is a collection of web pages that are accessed through the Internet. "Healthtalk.org provides the benefits of shared experience by publishing excerpts from rigorous research interviews with patients, contextualised with medical information" (Kidd and Ziebland, 2016, p273). Academics all over the world are using Healthtalk video clips in qualitative research. Published papers from 1995 onwards, included subjects such as, antidepressants, sleep, antibiotics, and obesity (Healthtalk, 2016b). Healthtalk data has also been used by academics researching autism (Ryan and Salisbury, 2012; Ryan, 2013).

The use of Healthtalk interviews as a data source has its advantages and limitations. Similarly to the advantages afforded by published books and YouTube, the author is the expert on the phenomenon that is being researched (Kidd and Ziebland, 2016). As described by these authors, the interviewees will have agreed in advance to the interview, know, and be in agreement with its purpose. A date and time will have been mutually agreed for the interview, and this will have provided the interviewee with time to retrospectively reflect, engage, and recall the meaning they described of an experience that may contribute to its accuracy. However, similarly to books, having to recall events from memory of an experience or event that occurred long ago can distort or omit details, and may result in a narrative that is exaggerated or over-elaborated (Mathias and Smith, 2016).

Unlike the autobiographical accounts published in books and YouTube video blogs, Healthtalk interviews have the advantage of being collected for research purposes using "rigorous qualitative research methods" (Kidd and Ziebland, 2016, p276). The National Health Service (NHS) National Knowledge Service stated the methods used by Healthtalk are "the 'gold standard' for research into patient experiences (Healthtalk, 2016c) and "have set the benchmark for research into health and illness experiences" (Gray, 2017, p1).

In summary, my choice of research methods allowed me to capture the meaning of sociality and friendship of persons with autism³⁶ from their perspective that reflected the differing preferences for storytelling environments that a person may have. Based on my examination of the literature, it was, therefore, essential for my choice of data sources to include on-and off-line storytelling environments. These were autobiographical accounts of persons with autism³⁷ published in books, YouTube video blogs posted by individuals who claimed they had the label of autism, and Healthtalk interviews of persons with autism. In the context of my ontological positionality, I valued all autobiographical accounts equally, whatever environment they originated from.

During the selection of my data sources, I recognised and reflected on my bias. In terms of my prior experience with YouTube, I have viewed relatively few video blogs and have never posted one. Whilst I had previously accessed the Healthtalk websites I had only done so to collect data for the pilot study I completed early in my professional doctorate. I had, however, read a number of autobiographical accounts in books written by persons with autism. My choice of data sources I hoped reflected my intention to engage in storytelling environments that were both familiar and unfamiliar to me. In doing so, I hoped I had recognised, reflected on and, therefore, reduced my bias in terms of my personal preference for storytelling environments.

Although my choice of data sources didn't place participatory demands on persons with autism, it presented me with an academic barrier in conducting emancipatory disability research. Emancipatory disability research is as claimed by several authors complex and difficult to achieve in practice (Oliver, 1997; Shakespeare and Watson, 2002; Barton, 2005; Danieli and Woodhams, 2005; Oliver and Barnes, 2010). Oliver (1997; p25) argued:

³⁶ The sources all claimed that they identified with the label of autism or AS. My use of existing data sources meant it wasn't possible for me to always ascertain whether a formal diagnosis had been obtained as I didn't have the opportunity to interact with the sources.

³⁷ My data collection included persons who referred to themselves as being on the autism spectrum or had AS in recognition that both labels are part of the same continuum.

Research can only be judged emancipatory after the event; one cannot 'do' emancipatory research (nor write methodology cookbooks on how to do it), one can only engage as a researcher with those seeking to emancipate themselves.

It is these academic barriers that I critically appraise in the next section of this chapter.

3.7 Academic barriers and emancipatory disability research

As described earlier in my thesis, to conduct emancipatory disability research requires compliance with the principles stated by Stone & Priestley (1996), and in particular with the values of empowerment, reciprocity and gain (Martin, 2015). Having presented my rationale for my choice of methodology and methods, I now critically examine whether my researcher positionality and research design could allow me to meet these three fundamental principles.

3.7.1 The principles of empowerment, reciprocity and gain

There is no agreed definition of empowerment (Hedges, 2007). Instead, this concept is regarded as a complex and multidimensional process rather than an event (Chamberlain, 2013; Smith, 2014). Smith (2014) claimed that empowerment was a much-used word that researchers had often taken for granted. Kitchin (2000, p26) in his work with people with disabilities defined empowerment as "seeking 'positive' individual change through participation". Nyatanga and Dann (2002, p235) defined the concept of empowerment as "a process and an outcome involving the individual or group's ability to pull from within themselves the power to influence or control significant events in their lives" that had the fundamental goal of well-being.

Research can only, therefore, be emancipatory if persons with disabilities have a participatory role and "pull from within themselves" (Nyatanga and Dann (2002, p235) the meaning they describe of their lived experience. For research to be empowering persons with disabilities need to be in charge of the project (Kitchin, 2000), i.e., the strategy, agenda, and questions need to be formulated

and directed by the persons with disabilities, to ensure that the power of research production remains with them. Using existing autobiographical accounts, that were already available in the public domain, didn't place the persons who had written the book, posted the YouTube video blog, or Healthtalk interview in charge of the research process. This led me to question whether listening to someone's stories, aspirations, and experiences of sociality and friendship was sufficient to achieve empowerment.

Reciprocity in research "describes the respectful nature of good research relationships and exchanges that are essential in participatory and other types of research" (Maiter et. al., 2008, p307). By using existing data sources, there was no opportunity for me to interact with the persons who had posted the YouTube video blog, Healthtalk interview, or written a book. The design of my research project presented me with an academic barrier to achieving the value of reciprocity.

With regard to gain my research needed to be of benefit to persons with autism. The aim of my research was to describe the meaning of sociality and friendship of persons with autism from their perspective, including identifying disabling social barriers and the ways that these could be overcome. This aim, therefore, aligned with this principle of emancipatory disability research.

Whilst I was able to meet the principle of gain, the design of my research didn't allow me to achieve those of empowerment and reciprocity, and led me to question whether my research could be positioned within the emancipatory disability research paradigm. Conducting emancipatory disability research is a complex issue that I now examine.

3.7.2 The complexities of emancipatory disability research

Several authors have critically examined the complexities of conducting emancipatory disability research (Chappell, 2000; Kitchin 2000; Barton, 2005; Johnson, 2009; Martin, 2015). These authors argued that whether research

could be regarded as emancipatory wasn't exclusively dependent on achieving the principles of empowerment, reciprocity, and gain.

Chappell (2000) wrote that it was the design and intentions that were the tenets that defined whether research could be regarded as emancipatory. As stated by Martin (2015, p211), there are other contexts in which research can be regarded as emancipatory such as "when the social relations of research production are more enabling". Barton (2005) claimed that persons with disabilities needed research to be useful and relevant. Kitchin (2000, p43) found persons with disabilities wanted "academics"³⁸ to be engaged in emancipatory and empowering research projects aimed at improving the lives of disabled people". Research into intellectual disability stated that to be emancipatory "The research question, problem or issue must be one that is owned (though not necessarily initiated) by people with intellectual disabilities" and "further the interests of disabled people: non disabled researchers should be on the side of people with intellectual disabilities" (Johnson, 2009, p252).

In support of my claim that I was doing emancipatory disability research, the design and intentions of my study were committed to acknowledging that the persons with autism were the experts on their lived experience. The aim of the outcome of my research, to contribute to resolving the conundrum of persons with autism socialising but finding it difficult to make friends and maintain friendships, I believe could be viewed as enabling and furthering the interests of persons with autism, may improve their lives, and be useful and relevant to them. Finally, my researcher positionality placed me firmly on their side. However, together with the complexities of meeting the criteria for emancipatory disability research, authors also claimed that such a project was problematic to achieve in practice (Oliver, 1997, Danieli and Woodhams, 2005). The next section examines these difficulties.

³⁸ Kitchin (2000) positioned the researcher as the non-disabled person.

3.7.3 The difficulties of doing emancipatory disability research

The difficulties of achieving an emancipatory disability research project in practice were critically appraised by several authors (Oliver, 1997; Shakespeare and Watson, 2002; Danieli and Woodhams, 2005; Oliver and Barnes, 2010). Oliver, stated, “While our intentions have been honourable, we remain on the wrong side of the oppressive social and material relations of research production” (1997, p24). Danieli and Woodhams (2005) claimed that the need for findings to support the social model of disability wasn’t always achievable if the outcome was political and not objective. These authors also critiqued the difficulties in addressing the power relationship between the researcher and researched. Danieli and Woodhams (2005) wrote that in trying to achieve the principles of emancipatory disability research, the ability of a researcher to generate knowledge could be undermined that may contribute to the emancipation of persons with disabilities.

Researching with social media and Internet data sources is a relatively new methodological approach (Harriman and Patel, 2014). From my perspective, what may be required is a reassessment of the methodological principles of emancipatory disability research to support the use of such data sources. Methodologists embrace innovation with caution, and this has included the Internet as a research medium (Lee, Fielding, and Blank, 2008). It may be that social media and websites are at present an emergent data source that may transform how research is practised in the future. Hodge concluded, “To be successful researchers need to engage with innovative and creative methodologies and to share their experiences of these within environments that welcome challenge and debate” (2008, p29). My use of YouTube video blogs, Healthtalk interviews, and autobiographical accounts in books I regard as a valid extension of existing methodology, but I’m happy for this to be challenged and debated.

For me, whilst acknowledging these academic barriers, whether asking if a piece of research about disability is emancipatory in nature or not, may not necessarily be the correct question to ask. The important issue to address is

that whatever approach is adopted, the research needs to have the potential to empower persons with autism. Academics need to research issues that are of importance to persons with disabilities and support them in terms of removing social barriers (French and Swain, 1997). These objectives were embedded in my research.

In summary, my choice of methods was *influenced* by emancipatory disability research principles and demonstrated my commitment to this research paradigm. My work can emancipate by presenting possibilities for an enabling narrative of sociality and friendship for persons with autism. Brownlow, O'Dell, and Bertilsdotter Rosqvist stated (2013, p91), "It is only through examining the important relationships between on and offline understandings and how these interconnect, will a full exploration of meanings be possible". My choice of an offline data source of published books, and online data sources of YouTube video blogs and Healthtalk interviews I claim allowed me to gain insight into the meaning of sociality and friendship of the persons with autism in my study from their perspective.

My approach enabled me to conduct research that I hoped would make a positive difference to the lived experience of persons with autism, furthering their interests and improving their lives, by contributing to overcoming disabling social barriers. As a researcher, I'm sharing my experience of working with on- and off-line environments, and I welcome challenge and debate to my choice of methodology.

Having provided the rationale for my qualitative enquiry, I now return to my choice of data sources and consider the ethical implications of this approach.

3.8 Ethical considerations

SHU requires all research to undergo ethical scrutiny, to ensure that the highest ethical standards are achieved and that the integrity of its' research is protected (SHU, 2016). Approval of my research project was received from SHU on 27th June 2014 (Taylor, 2014). As I obtained prior ethical approval from SHU, I don't

present in this section a detailed examination of the ethics of my philosophical and methodological framework. Instead, I now examine some of the issues related to my choice of emergent online environments as two of my data sources³⁹.

The Economic and Social Research Council (ESRC) provides information regarding the ethics of all research and specific guidance on Internet-mediated research (ESRC, 2017). Their guidance stated for research that involved social media, such as YouTube and Healthtalk, researchers needed to abide by the regulations set by the organisations that produced the data.

Healthtalk stated that researchers proposing to use their material should contact them for permission to do so (Healthtalk, 2016a). In 2013, Healthtalk were asked for and granted me permission to use their data. Their response to my request was they were “very happy and delighted that the project is being used” (Hodge, 2013).

YouTube have *Community guidelines* that present “a few ground rules to make sure that YouTube stays safe and fun for everyone” (YouTube, 2016a, no page number). The guidelines that are relevant to my use of YouTube video blogs are “respect the YouTube community” and “don’t cross the line” (YouTube, 2016a, no page number). The rule of respect concerns trusting the users of YouTube to act responsibly. Responsible use of data is a pre-requisite in academic research and applies to all data sources regardless of the environment in which they are generated. “Don’t cross the line” concerns the issue of copyright. The guidance provided an example of words spoken in a conversation between two friends that YouTube stated would “not be subject to copyright separately from the video itself unless they were fixed in advance” (YouTube, 2016b, no page number). Similarly, the words spoken by the persons with autism who posted a video blog that I chose as a data source weren’t decided in advance, and, therefore, not subject to copyright.

³⁹ The use of published autobiographical accounts of persons with autism in books as a data source is an established research practice (O’Neill and Jones, 1997; Chamak et. al., 2008; Elwin, et. al., 2012). The ethical implications of using this data source are as a result, not examined in detail in my thesis.

Wilkinson and Thelwall (2011) examined the ethical issues of researching with personal information from the Internet. These authors regarded the use of such data as reasonable in principle. Regarding anonymity, I chose not to anonymise my data sources. The persons with autism who had posted the video blog or Healthtalk interview included their name or another identifier such as a nickname and so had already renounced their anonymity. Wilkinson and Thelwall stated (2011, p397):

Revealing clues to the identity of an originator of some data analysed, such as their profile URL or an identifiable quote, is not breaching their anonymity but merely copying their identity from one public situation (the web) to another (an academic article).

This principle can also be applied to the copying of identities from Internet-based sources to my thesis⁴⁰.

With all the sources I used, the authors were fully acknowledged and their expertise valued. In my thesis, I described the findings of my research in ways that stressed the ownership of these accounts by those who had lived the experience. My research merely sought to capture the experience of sociality and friendship and describe the meaning that these phenomena had for the persons with autism in my study.

Having considered the ethical implications of my research, I turn my attention to how I collected and analysed my data, as described in the next sections of Chapter Three.

3.9 Data collection

To begin, I identified search terms that aligned with my focus of enquiry. These were autism, AS⁴¹, sociality, and friendship. Using these search terms, I now

⁴⁰ I acknowledge that my thesis will only become a public document once it is included in the SHU research archive.

⁴¹ I included AS as a search terms to acknowledge that persons don't always differentiate between the two labels of autism and AS.

describe how I selected my data sources from each of the autobiographical environments that I had chosen.

To collect my data, I commenced by exploring the Healthtalk website to identify relevant web pages. Autism was one of the 22 categories listed (AS wasn't presented as a category). The overview for this web page provided links to:

- Autism teaching resources
- Having a grandchild on the autism spectrum
- Having a sibling on the autism spectrum
- Life on the autism spectrum
- Parents of children on the autism spectrum.

As I was researching the perspective of persons with autism on sociality and friendship as described in their own words, I selected the link to "life on the autism spectrum". Interviews were presented under different sub-headings. Again, reflecting my focus of enquiry, I selected the links to interviews under the headings of "autism and friends" and "making friends, social life and autism"⁴². To identify and avoid bias, all interviews posted under these two topics were transcribed. For example, listed under "autism and friends" were eleven interviews. In addition, a second interview was transcribed for Catherine⁴³ (Healthtalk, 2014g)⁴⁴ posted under the topic "autism feeling different and wanting to fit in" (Healthtalk, 2014d). One interview was posted by the mother of a son with autism. As this interview didn't describe the meaning of sociality and friendship of a person with autism in their own words it was, therefore, excluded as a data source.

⁴² URLs for each of the Healthtalk web pages are listed in Appendix One.

⁴³ The additional interview was transcribed for Catherine (Healthtalk, 2014g) who had also posted under the topic of "autism and friends" to ensure that all the meaning that she had posted was transcribed.

⁴⁴ The URL for each Healthtalk source is listed in Appendix One.

The YouTube website was searched for video blogs using the search terms 'autism' or 'AS', each together with 'sociality' or 'friendship'. For example, autism and friendship generated over 57,000 results. As discussed, using the sampling strategy described in section 3.9.1, again, with the aim of avoiding bias, I selected YouTube video blogs, regardless of length, that had been posted by persons who stated they had a diagnosis of autism or AS or described themselves as identifying with these labels.

To identify books written by persons with autism or AS, relevant databases were identified from the SHU guidance on ebooks. At SHU students have access to the university's collection of full electronic books through dawsonera, Ebook library, EBSCOhost, MyLibrary, ScienceDirect, and VLe (SHU, 2017). Books that were written by persons with autism were identified through the use of the same search terms as YouTube video blogs. For example, searching dawsonera using the search terms 'autism' and 'friends' generated 77 results. Again to avoid bias, these results were then reviewed to identify as potential data sources all books whose author stated that they are a person with autism or AS. Once selected as a data source, using the sampling strategy described in section 3.9.1, each book was searched using the terms friend, friendship, and social. The use of these terms allowed me to identify what was important to the authors about their experiences of sociality and friendship. I now describe the sampling strategy that I used to identify my data sources from the list of YouTube video blogs and books that I had identified from my searches.

3.9.1 Sampling strategy

In general, the sampling strategy used in qualitative research is purposive in that "The researcher actively selects the most productive sample to answer the research questions" (Kerr, Nixon, and Wild, 2010, p271). My objective was, therefore, to use a sampling strategy that provided data that allowed me to capture the meaning of sociality and friendship for persons with autism. Bowen (2008) examined the concept of an appropriate sample and concluded that participants needed to best represent or have knowledge of the phenomena being researched. For YouTube video blogs and books, my intention was to

choose persons with autism who spoke or wrote about their lived experience of sociality and friendship, and who would be able to assist with my research, and enable me to answer my research questions. I, therefore, undertook quota sampling to gather representative data from a subgroup of video blogs and books listed as search results (Cohen, Manion, and Morrison, 2004). As stated by these authors, “a quota sample strives to represent significant characteristics (strata) of the wider population” (2004, p103). In devising my quota sample, I, therefore, aimed to reflect any significant characteristic in the general population with autism.

My review of the literature found that there is a strong male bias in the number of persons diagnosed with autism (Davidson and Smith, 2009; Werling and Geschwind, 2013). My selected characteristic, was, therefore, gender that resulted in two categories, men with autism and women with autism. The male bias of persons with autism found in the general population was reflected in my quota sample or proportion of men with autism and women with autism in each category, i.e., fourteen of my data sources were female and twenty-seven male⁴⁵).

I acknowledge there are limitations and advantages to using a quota sampling strategy (Ritchie, Lewis, and Elam, 2003). Quota sampling tends to be biased towards people who are willing, easily accessible, and interested in the issue that is being researched (Yang and Banamah, 2014), isn't representative of the population as a whole and doesn't allow sampling error to be assessed (Im and Chee, 2011). Conversely, quota sampling is easy to use and doesn't require sophisticated research skills (Im and Chee, 2011). In addition, other researchers have suggested that quota sampling is the preferred sampling strategy for Internet-based studies as probability sampling isn't possible, and was regarded by some authors as the standard method (Im and Chee, 2011). These authors found that in their Internet study quota sampling was critical to recruiting participants for their research. A Quota sampling strategy has also

⁴⁵ I assumed that the male bias for persons diagnosed with autism was also reflected in the Healthtalk interviews.

been used by other academics when researching autism (Ho et. al., 2014; Burke et al., 2016).

I tried to be objective in my sampling strategy. However, the order in which the search results were presented by YouTube and the SHU library was a product of the search engines used. Algorithms will have sorted the results and placed the ones judged to be the most relevant at the top of the search engine results page. To avoid bias and subjectivity, I chose video blogs and books that represented as diverse a cross-section of the population of persons with autism as possible. I also acknowledge that my choice of data sources may have been unconsciously influenced by my researcher positionality and any personal bias that I may hold for a particular gender, age group etc. I recognise, therefore, that my choice of quota sampling is open to academic scrutiny and debate.

As previously stated, ensuring that the outcome of my research was regarded as trustworthy was a key consideration in my study as this signified confidence in my findings (Lincoln and Guba, 1985). To do so, I needed to ensure that I collected sufficient data for my study or achieved the data saturation point. I examine in the next section how I defined and demonstrated that the data saturation point was reached.

3.9.2 Saturation point

There is no definitive answer to the quantity of data that a researcher needs to collect (Opie, 2004). What is required is for the data saturation point to be achieved. The point at which data saturation is achieved, therefore, defines the sample size (Kerr, Nixon, and Wild, 2010). The concept of the data saturation point has been the subject of extensive discourse in the academic literature and was acknowledged as being difficult to define (Bowen, 2008; Mason, 2010; O'Reilly and Parker, 2012; Fusch and Ness, 2015). Knowing when data saturation has been achieved is a challenge to many qualitative researchers. O'Reilly and Parker (2012, p191) wrote that "Saturation seems to have become the gold standard against which the diversity of samples is determined and yet saturation has multiple meanings and limited transparency".

Fusch and Ness (2015) undertook a detailed examination of the published literature on data saturation. A key consideration was in determining when data saturation point had been reached is obtaining rich (quality) and thick (quantity) data. As described by these authors:

Thick data is a lot of data; rich data is many-layered, intricate, detailed, nuanced, and more. One can have a lot of thick data that is not rich; conversely, one can have rich data but not a lot of it. The trick, if you will, is to have **both**. (Fusch and Ness, 2015, p1409).

Mason (2010) analysed the sample size in over 2,500 doctoral studies that used qualitative interviews. This author found that a wide range of sample sizes was used with the average being 28. Brod, Tesler, and Christensen (2009) provided a summary of how the method used to collect data influenced the data saturation point. 12 interviews, or between 4 to 6 focus groups were cited by these authors as the point at which data saturation would generally have been achieved. Alternatively, these authors stated that a combination of 3 to 4 focus groups and 4 to 6 interviews would typically achieve the same aim. Recent guidelines for thematic analysis by Braun and Clarke (2013) recommended for medium projects, such as a professional doctorate, 10 to 20 interviews, 3 to 6 focus groups, or more than 30 diaries. As observed by Fugard and Potts (2015) it wasn't clear how these numbers were determined. Ando, Cousins, and Young (2014) modified the method for thematic analysis of Braun and Clarke (2006) and concluded that 12 interviews were sufficient to reach data saturation.

The sample size to achieve saturation point will, therefore, vary between studies and will be achieved when the research questions can be answered (O'Reilly and Parker, 2012). Answers to research questions and, therefore, data saturation, is reached when: 1) there is sufficient data to replicate the study; 2) there is no further opportunity to gather additional data; and 3) when it isn't possible to assign further coding to data (Fusch and Ness, 2015). To achieve data saturation, I, therefore, needed to adopt a pragmatic and flexible sampling strategy and to obtain data that was both rich and thick that enabled me to answer my research questions (O'Reilly and Parker, 2012).

Similarly to defining the data saturation point, how the researcher demonstrates that this point has been reached has also been the subject of extensive academic discourse (Bowen, 2008; Brod, Tesler, and Christensen, 2009; Fusch and Ness, 2015). Again, there are no explicit guidelines on this subject resulting in ambiguity (Ando, Cousins, and Young, 2014). At the same time what is required is a process that is rigorous, thorough, and transparent (Bowen, 2008). Demonstrating that the saturation point has been reached, therefore, is a difficult process. This often involves making a qualitative judgment backed up by notes and transcripts that evidence “Key sample characteristics and concepts have been sampled” and “No new information is being generated” (Brod, Tesler, and Christensen, 2009, p1268).

An initial judgment to demonstrate that the saturation point has been achieved can, however, be made by constructing a saturation grid or table (Brod, Tesler, and Christensen, 2009, Kerr, Nixon, and Wild, 2010). Topics are listed against data sources. When the grid column for the current group is empty, no new themes or concepts have emerged and, therefore, the saturation point is deemed to have been reached (Brod, Tesler, and Christensen, 2009). My intention was that by providing evidence of data saturation together with evidence of trustworthiness (Lincoln and Guba, 1985) that this would signify confidence in my findings (Bowen, 2008).

Each YouTube video blog, Healthtalk interview, or book was transcribed verbatim as a written record. Appendix One lists and presents a brief description of each source that reflected the level of detail available. Sources are presented in the random order that their account was transcribed. All YouTube video blogs and Healthtalk interviews were listened to and observed.

Data were collected and transcribed in four periods, October 2014, January 2015, September 2015, and November and December 2015. At the end of each period, I constructed a saturation table and the one for October 2014 is shown in Appendix Three. Between these dates, I reflected on the data I had transcribed in the previous transcription period, in terms of the meaning of sociality and friendship that the sources had described. I reflected upon my

initial thoughts as to what was interesting about my data and the quantity of data that I had collected with the intention that data collection continued until “saturation” had been achieved (Brod, Tesler, and Christensen, 2009).

After listening to and observing eleven video blogs, twenty online interviews, and reading ten autobiographical accounts published in books, over a period of approximately fifteen months I anticipated I may have gathered sufficient data to reach the saturation point. To make this preliminary judgment as to whether I had done so, I constructed a saturation table. (Brod, Tesler, and Christensen, 2009). For each of the topics in the table I concluded that the saturation point had been reached as: 1) there was sufficient data to replicate the study; 2) there was no further opportunity to gather additional data; and 3) it wasn't possible to assign further coding to data (Fusch and Nesh, 2015). I would return to make a final judgment as to whether the data saturation point had actually been reached later during the analysis (coding) of my data (Brod, Tesler, and Christensen 2009).

Having collected my data and made a preliminary assessment that I had achieved the data saturation point, I turned my attention to the analysis of my data. The objective of my analysis was to describe the meaning of the sociality and friendship experiences of the sources from their perspective. Common experiences are regarded in qualitative research as themes. Section 3.10 describes the process of thematic analysis (Braun and Clarke, 2006) that I used and summarises the themes that I identified.

3.10 Data analysis

To identify the meaning that the sources in my research described of their experiences, I needed to identify a qualitative analytical method that would best allow me to identify their common experiences.

I reflected on the data I had transcribed and concluded I needed to identify a method that aligned with my theoretical position, researcher positionality, methodology, choice of data sources, and method of data collection. The

method that most closely met these requirements was thematic analysis. As defined by Braun and Clarke (2006, p79) thematic analysis is “a method for identifying, analysing and reporting patterns (themes) within data”. My appraisal of this method identified that it was used widely in qualitative research⁴⁶, could be used with any research theory, allowed a rich description of a data set, and didn’t require the researcher and the source to interact to co-create data (Braun and Clarke, 2006; West, 2013). Braun and Clarke (2006, p78) stated that thematic analysis was a “foundational method for qualitative analysis” that was suited to students early in their research career such as myself as it was an accessible form of analysis and taught key skills that could be applied to future projects. In addition, these authors also claimed that thematic analysis maybe a useful method when the focus of enquiry was an under-researched area such as the meaning of sociality and friendship for persons with autism from their perspective (Braun and Clarke, 2006).

Braun and Clarke (2006) wrote there were a number of questions that needed to be asked or decisions made by the researcher prior to analysis commencing. These were deciding: 1) what counted as a theme; 2) the type of analysis that I was conducting; 3) the approach I was using to identify my themes; 4) the level at which I was identifying my themes; and 5) the paradigm within which I was conducting my thematic analysis. I now present the rationale for these decisions that I made.

3.10.1 What counted as a theme

A theme “represents some level of patterned response or meaning within the data set “(Braun and Clarke, 2006, p82). Prevalence in thematic analysis needs to be considered within each data item (e.g., a YouTube video blog) and across the data set or all the data that I was analysing. As stated by these authors determining prevalence is complex and there is no right or wrong way in which to do so. The important issue is that within a research project that a consistent

⁴⁶ There are other versions of thematic analysis that I could have used to identify and analyse patterns in my data (Braun and Clarke, 2013). My choice reflected my familiarity with this approach that I had previously used in my EdD research.

approach is adopted. Based on my examination of the concept of prevalence as described by Braun and Clarke (2006), I adopted their convention, i.e., that prevalence was a meaning described by many or the majority of the sources. I acknowledge that as claimed by these authors there is no definitive figure as to the proportion of a data set that needs to exhibit evidence of the theme for it to be considered one. However, based on my reading of the literature, I decided that two-thirds of the sources needed to display the same meaning for it to be regarded as a theme. In adopting this criterion, my aim was to ensure consistency and avoid bias in how I determined prevalence and decided what counted as a theme.

3.10.2 The type of analysis conducted

As summarised by Braun and Clarke (2006), my choice was between producing a rich description of my data set or a detailed description of one particular feature. To answer my research questions, I felt that a rich description of my complete data set was required to enable the reader to gain an understanding of the important themes. I, therefore, aimed to identify themes that were an “accurate reflection of the content of the entire data set” (Braun and Clarke, 2006, p83). These authors wrote that in doing so, although I may sacrifice some of the depth and complexity of my analysis that my choice of a rich description was suited to investigating a poorly researched area such as the sociality and friendship of persons with autism from their perspective.

3.10.3 The approach used to identify themes

Braun and Clarke (2006) described that themes in thematic analysis can either be identified using an inductive approach, where themes are strongly linked to the data or deductively where the researchers theoretical perspective influences how the themes are identified. As claimed by these authors, an inductive approach provides a richer description of the data. In addition, adopting an inductive approach allowed me to use a range of codes without being influenced by the themes that previous researchers had identified. Adopting an inductive or data-driven approach to my thematic analysis that didn't require me

to try to fit my data into an existing coding frame, I hoped would allow me to reduce any bias in my thematic analysis⁴⁷.

3.10.4 The level of theme identification

Braun and Clarke (2006) claimed that whether an approach to thematic analysis could be described as descriptive or interpretive was determined by whether the themes were identified at either a semantic (explicit) or a latent (interpretive) level. As described by these authors, semantic themes reveal the surface meanings of data. In contrast, latent themes seek to identify deeper meanings and seek out the hidden or underlying ideas, assumptions, or conceptualisations that underpin semantic themes. I regard the themes that I had identified as being semantic or explicit, i.e., I wasn't looking for anything beyond what a source said or wrote about their experience of sociality and friendship, and I was undertaking descriptive thematic analysis. (My first research question presented in Chapter One specifically stated that my research aimed to describe the meaning of sociality and friendship of persons with autism). However, as stated by Braun and Clarke (2006), I aimed to progress in my analysis to theorising the significance of the themes, their wider meanings, and implications. These wider meanings and implications I examine in relation to the published literature in my discussion that I present in Chapter Five.

I acknowledge that there is a fine line dividing describing and interpreting data. The literature referenced the continuum of description to interpretation, i.e., the degree to which data is transformed during its' analysis (Sandelowski and Barroso, 2003). Vaismoradi, Turunen, and Bondas (2013) stated that many researchers claimed that descriptive and interpretive approaches both involved interpretation. As stated by Sandelowski (2000, p335), "Descriptions always depend on the perceptions, inclinations, sensitivities, and sensibilities of the

⁴⁷ As stated by Braun and Clarke (2006), I acknowledge that I didn't complete my coding in an "epistemological vacuum" and, therefore, my coding may have been influenced by my researcher positionality. Furthermore, whilst I was recognising and reflecting on my bias I couldn't assume that unconsciously that some remained during my coding.

describer". Qualitative descriptive studies, however, were positioned in the literature as being less interpretive than interpretive ones and resulted in findings closer to the data as it was given (Sandelowski, 2000 and 2010). In my descriptive thematic analysis, I strived, therefore, at all times to only describe the meaning of the sources and answer my research questions and, therefore, avoid bias.

3.10.5 Choice of research paradigm

As I have previously stated in my thesis, my research was *influenced* by emancipatory disability research principles and demonstrated my commitment to this research paradigm. I argue that my work can emancipate by presenting possibilities for an enabling narrative of sociality and friendship for persons with autism. Braun and Clarke (2006) stated that thematic analysis could be conducted within either an essentialist or constructionist paradigm. What will differ is the outcome and focus of the thematic analysis.

In deciding on the approach to adopt, I reflected on my researcher positionality. As I have previously stated in my thesis, I believe there are many different versions of reality and that an individual is unique and strongly influenced by social positioning. The meaning of sociality and friendship for persons with autism is, therefore, "socially produced and reproduced" (Braun and Clarke, 2006, p87). I was, therefore, undertaking transformative thematic analysis. As stated by Braun and Clarke (2006) thematic analysis can be used with any research theory. Similarly to the constructionist paradigm referred to by these authors, the transformative paradigm in which emancipatory disability research is positioned often uses a qualitative methodology and methods but also allows research "to be intertwined with politics and a political agenda" as reflected by the influence of emancipatory disability research on my focus of enquiry (Creswell, 2003, p9). My research will, therefore, "seek to theorise the socio-cultural contexts, and structural conditions" of the autobiographical accounts of the sources and the semantic themes that I had identified (Braun and Clarke, 2006, p85).

3.10.6 Summary

In summary, as presented by Braun and Clarke (2006), prior to undertaking my thematic analysis I made a number of key decisions aimed at ensuring confidence in my findings that recognised and reflected on my bias to ensure that the outcome of my research was trustworthy (Lincoln and Guba, 1985). These decisions are summarised as follows:

- A theme was a meaning described by at least two-thirds of the sources
- Data was collected that was both thick and rich
- Data collection continued until the data saturation point had been reached
- Themes were identified that were an accurate reflection of the entire data set
- An inductive or data-driven approach was adopted to identify semantic themes
- My research demonstrated my commitment to the emancipatory disability research paradigm.

Adopting this approach allowed me to theorise the significance of my themes, their wider meanings, and implications for the meaning of sociality and friendship as described by the persons with autism in my study. Braun and Clarke (2006) wrote that the researcher needed to revisit these decisions they had made during the completion of their thematic analysis. I, therefore, reflected on my answers to these key questions during the completion of my thematic analysis as described in section 3.11.

Thematic analysis (Braun and Clarke, 2006) consists of a six-phase process:

- Phase 1 – familiarisation with the data

- Phase 2 – generating initial codes
- Phase 3 – searching for themes
- Phase 4 – reviewing themes
- Phase 5 – defining and naming themes
- Phase 6 – producing the report.

Whilst I'm describing the six phases in numerical order, I recognise that completing my thematic analysis wasn't a linear process. In completing my analysis, I moved back and forth between the phases to allow my analysis to develop and themes to be identified (Braun and Clarke, 2006). I present the first five phases of my thematic analysis in sections 3.11.1 to 3.11.5 of this chapter together with the process used for phase six. The report I produced for phase six is presented in Chapter Four.

3.11 Thematic analysis

3.11.1 Familiarisation with the data

As stated by Braun and Clarke (2006, p88) "There is no one set of guidelines to follow when producing a script". My chosen approach was to transcribe all interviews, video blogs, and accounts in books using Microsoft Word as this was the graphical word processing program that I was most familiar with. Transcribing the data took longer than I anticipated. Healthtalk provides written transcripts of online interviews that were an accurate representation of the spoken word. The YouTube transcriptions were of much poorer quality. The transcriptions of video blogs contained words that didn't exist and sentences that didn't accurately reflect the words spoken. Books had to be searched rigorously for relevant content, as many authors had written about their life experiences that weren't just confined to sociality and friendship. Authors in books often presented lengthy narratives that required a long time to transcribe.

Once all Healthtalk interviews, YouTube video blogs, and autobiographical accounts published in books had been transcribed, I read and re-read the data and noted down initial ideas. Comparing the transcripts between sources illustrated how differently people talked about the same subject. These differences reflected the language used by the Healthtalk sources and some book authors who were mainly British, and the predominantly American YouTube sources, and other authors of books. American sources, e.g., ErinClem (YouTube, 2012c) and Victoria (YouTube, 2013) used the word 'awesome' and Simone (2010) and Harris (2015) used the phrase 'hang out'. British sources used other words, e.g., 'amazing' (James, Healthtalk, 2010a), 'fine' (Brown, 2008), and 'happy' (Mary, Healthtalk, 2010l; Ben, YouTube, 2012b; Richard, Healthtalk, 2014e).

All sources, regardless of the words spoken or written, were using their preferred terminology to describe their meaning of sociality and friendship. The disparity in the language used merely reflected the cultural differences of the sources. The impact of culture on research has been the subject of academic discourse. Visby-Sniker (2010) concluded that cultural differences needed to be included and acknowledged in research, but didn't present insurmountable issues in methodology. I considered these culturally based language differences when familiarising myself with the data, to ensure that I avoided bias and correctly described the meaning of sociality and friendship as described by the sources. I read and re-read my data in an active way looking for meanings or patterns. The writing was an integral part of my analysis, and I began to write in stage one jotting down ideas and potential coding schemes. My initial ideas were recorded as comments aligned with the text (See Appendix 2.1).

If my process of coding was to be successful, I needed to familiarise myself with the depth and breadth of the content of my data and this varied between sources. Victoria (YouTube, 2013), Arman (YouTube, 2012a), and ErinClem (YouTube 2012c) talked at length about their lived experience of sociality and friendship. The authors of some of the published books spoke exclusively about sociality and friendship (Brown, 2008; Harvey, 2008; Jarvis, 2008). Ian (Healthtalk, 2010g), Mark (Healthtalk, 2010d), and Sam (Healthtalk, 2014f) said

comparatively little, whilst other authors of books (McCabe, 2003; Pears, 2004; Simone, 2010) also described the meaning of other phenomena. In recognising and reflecting on my need to avoid bias, this didn't mean that any of the accounts were of less importance than others.

I found it helped to listen to the Healthtalk interviews and YouTube video blogs on several occasions. I listened to the online sources whilst observing the interview or video blog, and whilst reading the transcripts that I had transcribed. I also read the transcripts without observing the video blog or online interview. Transcripts of autobiographical accounts in books were also re-read on several occasions. For online sources repeated observations of data allowed me to focus on how sentences were spoken, and this enhanced the meaning I found in my data. Familiarising myself with the data also involved taking notes and marking the text by adding comments linked to an excerpt of raw data. Comments I made included 'tried hard but failed to make a friend', 'body language', 'social skills training', and 'anticipating understandings'.

Throughout phase one of my thematic analysis, I reflected on my decision to provide a rich description of my entire data set. I had collected a large quantity of rich and thick data from that I had identified many ideas of what appeared interesting to me. From my reading of Braun and Clarke (2006) I, therefore, decided that my decision to present a rich description of the entire data set was appropriate. Once I had reached the stage where I felt familiar with my data set, I moved on to phase two generating initial codes.

3.11.2 Generating initial codes

I initially found this process more difficult than expected. This may have been due to the technique being relatively new to me⁴⁸. I aimed to code my data set systematically and consistently using the same term for a code. For instance, 'positive experience' was used rather than 'good experience'. I was conscious not to miss any significant findings through incomplete or incorrect coding, and

⁴⁸ I had used thematic analysis (Braun and Clarke, 2006) once before for my pilot study in my EdD.

not to introduce a new code and over complicate my analysis. On each occasion, I returned to phase two over several days examining my coding of all data sources to ensure consistency.

Initial codes that I assigned included 'assumes choice', 'negative experience', 'normalcy', 'ableism', and 'misunderstandings'. I tried to use open coding or coding anything that might be relevant including the behaviours, values, and emotions described by the sources. When all my data had been coded and collated, I had generated an extensive list of different codes identified across my data set. An example for Arman (YouTube, 2012a) is shown in Appendix 2.2.

In recognising and reflecting on my need to avoid bias, my aim during the coding process was to give full and equal attention to all data items. This helped me to identify interesting aspects that formed the basis of repeated patterns or themes across the entire data set. I coded for as many potential themes as possible, probably coding more of an extract of data than was required, to ensure that I retained the meaning and context. For many data items, more than one code was assigned. Examples of coding were 'successful strategy', 'advice on making friends', and 'job as opportunity'. Again, to avoid bias, I didn't ignore contradictions in my coding and coded for anything of relevance. Some sources talked about positive and negative experiences of friendship (e.g., Mary, Healthtalk 2010I; Victoria, YouTube, 2013; Harris, 2015). On occasions I applied more than one code to an extract of text (e.g., "most of them have been really great friendships" was coded for "positive experience" and "had great friends"). At the end of phase two, I had generated an initial list of ideas or codes about what was interesting in the data to me.

As stated in section 3.10.3, my thematic analysis and, therefore, my coding, was data-driven or inductive (Braun and Clarke, 2006) and consistent coding of my data was of critical importance⁴⁹. My aim of adopting an inductive approach was to complete the coding process without forcing data into a pre-existing

⁴⁹ In qualitative research consistent coding is often achieved by having more than one researcher coding the data. In a doctoral thesis, I acknowledge that this wasn't possible.

coding frame. Coding continued to be developed and defined throughout the entire analysis reflecting that this wasn't a linear process.

Throughout my thematic analysis, I moved between phases. This resulted in some coding being undertaken during the later phases of my analysis. Coding allowed me to organise my data into meaningful groups and to move on to phase three searching for themes. During phase two of my thematic analysis, I returned to consider whether I had reached the data saturation point. During the first three periods in which I collected data, October 2014, January 2015, and September 2015 I concluded that I hadn't yet done so. In reaching this conclusion, at the end of each of these time periods I constructed a saturation table and concluded that I hadn't yet met the criteria I had identified in section 3.9.2, i.e., 1) there was insufficient data to replicate the study; 2) the opportunity to gather further data still existed; and 3) it was possible to assign further coding to the data (Fusch and Nesh, 2015). For example, at the end of the third period of data collection, I introduced the code "older people as friends". During my fourth phase of data collection in November and December 2015, this code was assigned to further data extracts. From my reading of the literature, at the conclusion of my fourth period of data analysis, I concluded that the three criteria I had identified to achieve data saturation had been met and that no additional data needed to be collected (Brod, Tesler, and Christensen, 2009).

During phase two I again revisited the decisions I had made prior to commencing my thematic analysis. Given the comprehensive coding that I had completed and as evidenced by the literature, adopting a data-driven or inductive approach to my thematic analysis was the most appropriate choice to make. Having reached data saturation point I moved on to phase three, searching for themes.

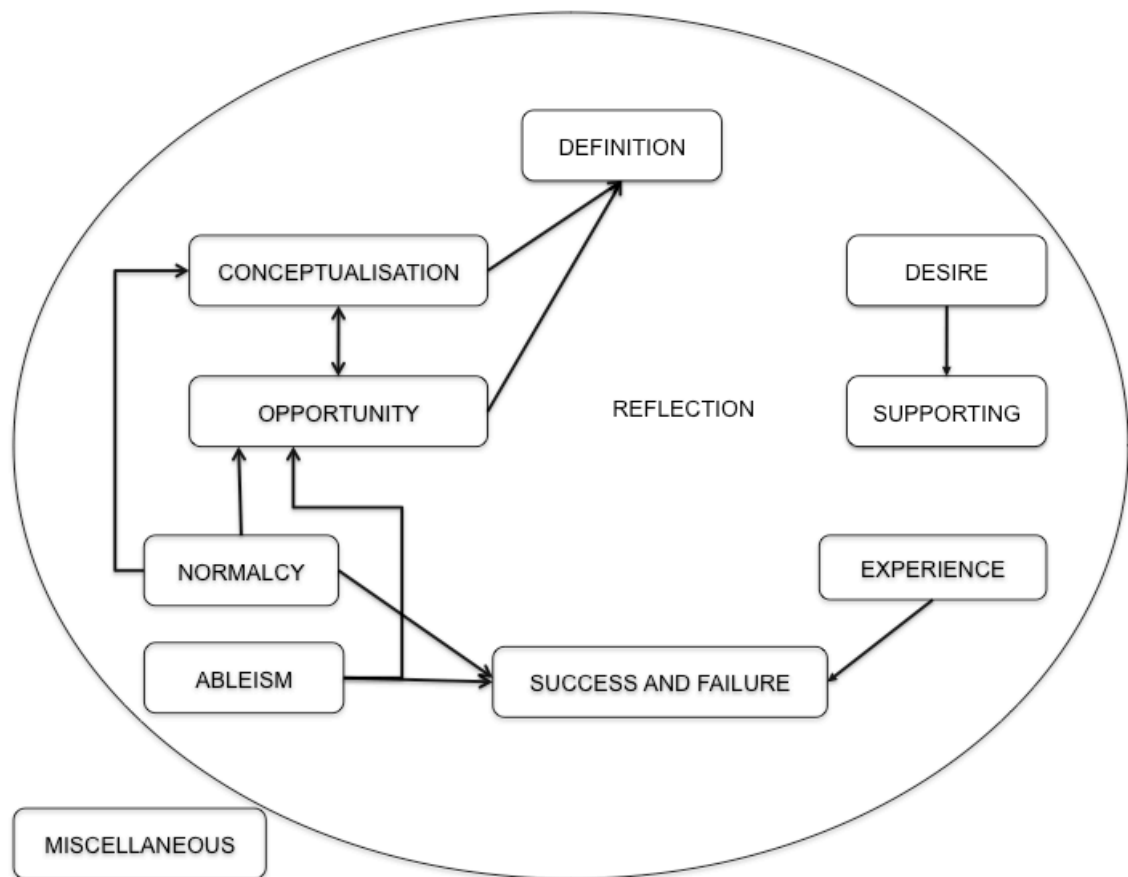
3.11.3 Searching for themes

In searching for potential themes, I listed all the codes with the expectation that themes would naturally emerge (examples of the themes of experience and ableism are presented in Appendix 2.3). Braun and Clarke (2006) make some

interesting observations as to what counts as a theme. As I examined in section 3.10.1, prevalence is a key consideration in searching for themes both within a data item and across a data set. This doesn't mean that a theme is only associated with multiple appearances within a data item or across a data set. It was for me to make judgments as to what data constituted a potential theme. The issue was whether the data captured something important with respect to my research questions. Thematic analysis allows the researcher to identify the important themes that are reflected across an entire data set, and I searched for potential themes on this basis.

Whilst some codes were easily grouped together, for example 'negative experience' and 'difficult to make friends', others such as, 'environment' and 'culture' appeared isolated. In recognising and reflecting on my need to avoid bias, at this stage, no codes were dismissed. Phase three of my thematic analysis was completed when I had a list of potential themes. Eleven potential themes were identified including those that appeared isolated, that I labelled 'miscellaneous'. The other ten themes were ableism, conceptualisation, definition, desire, experience, normalcy, opportunity, success and failure, supporting, and reflection. From my eleven potential themes, I produced my first thematic map as depicted in Figure Two:

Figure Two⁵⁰



Initial thematic map of the meaning of sociality and friendship for persons with autism

In Figure Two, success and failure in socialising, making friends and maintaining friendships, were informed by the candidate themes of experience, normalcy, and ableism. Ableism influenced the opportunities that sources thought they had to be social and make friends, and normalcy influenced both the candidate themes of opportunity and conceptualisation. The meaning of opportunity was synonymous with how sources conceptualised sociality and friendship, and both these candidate meanings shaped the definition of sociality and friendship for the sources. Sources frequently desired to be social and to have friendships. For some sources supporting other persons with autism in achieving these aims was an integral part of this desire. Many sources reflected on their experiences of sociality, making friends, and maintaining friendships.

⁵⁰ Boxes in Figure Two that aren't linked didn't influence each other.

Finally, there were several codes that appeared isolated, or didn't align with any other codes, and were depicted as being external to the meaning of sociality and friendship for the sources.

Whilst searching for themes I reflected on the decisions I had made prior to commencing my thematic analysis. In particular, my data supported the identification of semantic themes as this allowed me to describe the meaning of sociality and friendship of the sources by staying close to the data as given and answering my research questions. Having produced my initial thematic map, I now had a collection of candidate themes and moved to phase four reviewing themes.

3.11.4 Reviewing themes

I commenced phase four of my thematic analysis with eleven potential or candidate themes. My aim in reviewing my themes was to have coherent data within a theme and distinct differences between themes. This phase is about refining themes and involved a two-stage review process that I refer to as level one and level two (Braun and Clarke, 2006). Prior to commencing my level one review, I scrutinised my potential themes in terms of rigour, repetition, and embedded meanings. The candidate theme of 'supporting' was only coded in four data extracts. There was insufficient data to support this construct as a theme, and I aligned this code with another candidate theme that of 'desire'.

My candidate themes of 'conceptualisation' and 'opportunity' contained many of the same codes. How a source conceptualised sociality and friendship were also seen as an opportunity to socialise and to make friends. Examples included conversation, sharing activities, or interests. I collapsed these two candidates themes into one and renamed it 'process' that described how sources socialised, made friends, and maintained friendships.

I coded numerous excerpts of text and assigned them the code of 'reflection'. Sources frequently reflected on how their experiences of sociality and friendship made them feel, or how having friends and not having friends had affected them

emotionally. I felt this candidate theme should be renamed to reflect the emotional function that sociality and friendship represented for the sources. Consequently, I re-assigned the candidate theme 'reflection' the name 'function' and re-labelled the code 'reflection' to represent an emotional meaning, for example, 'happy' or 'regret'. The candidate themes of 'success and failure' and 'experience' shared numerous codes. These two terms could be used interchangeably as a positive experience could be regarded as a success and a negative experience as a failure. These two themes were merged as 'success and failure'.

I then reflected on what success and failure meant in terms of ableism and normalcy. Many sources judged the success or failure of their sociality and friendship experiences in terms of the benchmark of the PNT meaning of these phenomena. This judgement reflected the concepts of normalcy and ableism. Sources judged that the correct way to socialise, make friends, and maintain friendships was that of the PNT. Codes aligned with the candidate theme of 'normalcy' were, therefore, embedded in 'success and failure' and 'process' as appropriate. Similarly, the candidate theme of 'ableism' was assimilated into the theme of 'success and failure' as this theme described occasions when the sources had described the PNT meaning of these phenomena.

Having rationalised my candidate themes from eleven to five (desire, definition, function, process, and success and failure), I completed the two-stage review process (Braun and Clarke, 2006). My level one review of themes against coded extracts formed a coherent pattern. My theme of 'desire' aligned with the codes of 'wants friends', 'assumes persons with autism want friends', and 'strong aspirations for a particular friend'. Similarly, the theme of 'success and failure' aligned with the codes of 'negative experience', 'has friends', and 'surprised at success'. My level two review of themes against the entire data set identified a similar level of coherence as for a chosen theme the codes aligned across data sources. The theme of 'process' coded for 'activities as friendship' for Simone (2010), James (Healthtalk, 2010a), Sillygayboy (YouTube 2011b), and Richard (Healthtalk, 2014b). The theme of 'definition' for Lawson (2001),

Victoria (YouTube, 2013), Alex (YouTube, 2014a), and Nathan (YouTube 2014b) all coded for 'desirable qualities in people'.

After refining my thematic map produced in phase three, I reflected on the decisions I had made prior to commencing my thematic analysis. Based on my examination of the concept of prevalence as described by Braun and Clarke (2006), many or the majority of the sources described each theme. From my reading of the literature, to avoid bias, it was essential for my definition of prevalence to be applied consistently to my thematic analysis. At least two-thirds of the sources displayed the same meaning and, therefore, these patterned responses counted as themes.

Reflecting on my analysis at the end of this phase, I felt I had gained an understanding if incomplete, of the themes that represented the meaning of sociality and friendship for persons with autism from their perspective. An example of the end product of phase four is shown in Appendix 2.4. What was required to complete my understanding was the defining and naming of these themes.

3.11.5 Defining and naming themes

The defining and naming of themes is as argued by Braun and Clarke (2006, p92), the process of "identifying the 'essence' of what each theme is about (as well as the themes overall), and determining what aspect of the data each theme captures". I needed to determine what was interesting about a theme, and why it was so. A successful outcome for stage five of my thematic analysis was represented by a succinct and clear description of each theme.

My analysis of the data evidenced that the sources described meaning from their lived experience of sociality and friendships. For the persons with autism in my study, I presented their meaning of these phenomena as themes. As I had previously specified a theme was a meaning described by many or the majority of the sources. To count as a theme, at least two-thirds of the sources needed to display the same meaning. 70% of the sources displayed the meaning of the

function of sociality and friendship, 82.5% definition and process of sociality and friendship, and 85% desire for and success and failure in sociality and friendship. Having exceeded the threshold of two-thirds for all themes, I concluded that I had sufficiently recognised and reflected on my bias throughout the thematic analysis of my data. In addition, I concluded that the saturation point had been reached as: 1) there was sufficient data to replicate the study; 2) there was no further opportunity to gather additional data; and 3) it wasn't possible to assign further coding to data (Fusch and Nesh, 2015).

A detailed description and analysis of my themes, including examples from the sources, is presented in Chapter Four, and briefly summarised as follows:

- **Theme One – Desire for sociality and friendship.** Sources desired to be social and have friends and friendships, and some assumed that other people with autism shared this desire. Sources frequently said that they had socialised in the past, made friends, and maintained friendships. Many sources described their current experiences of sociality and friendships. A number of sources said that they wanted to socialise in the future to make friends. Several sources also claimed to know the meaning that other persons with autism described of these phenomena and wanted to support them in achieving their desire for sociality and friendship. Friendship was desired predominantly with people, but some sources desired objects or animals as friends.
- **Theme Two – Definition of sociality and friendship.** Many sources defined sociality and friendship in various ways. This included the size of social and friendship groups, the sharing of activities and experiences, and physical space, or virtual environments. Other definitions included different people as friends and desirable personal qualities in people who the sources wanted to socialise and make friends with.
- **Theme Three – Function of sociality and friendship.** Many sources described whether sociality and friendship had enabled them to make an emotional connection with someone, removed negative emotional states, or

resulted in a positive cognitive experience. Sources frequently reflected on how their past experiences of sociality and friendship had made them feel. The persons with autism in my study described many more instances of negative emotional states than positive ones that had resulted from their experiences of sociality and friendship.

- **Theme Four – Process of sociality and friendship.** Many sources described different opportunities they had used to socialise, make friends, and maintain friendships with different types of people. Some sources also described what had on occasions prevented them from socialising, making friends, and maintaining friendships.
- **Theme Five - Success and failure in sociality and friendship.** Sources described their successful and failed experiences of socialising and friendship. More instances of failing to socialise, make friends, and maintain friendships than successes were described by the sources. Some sources claimed to know that their experiences were shared with other persons with autism. Several sources talked about strategies they had used. These strategies they thought had enabled them to be more successful in socialising, making friends, and maintaining friendships. These sources recommended their strategies to other persons with autism as ways to socialise, to make friends, and maintain friendships. Some sources compared their degree of success in socialising and making friends to that of the PNT.

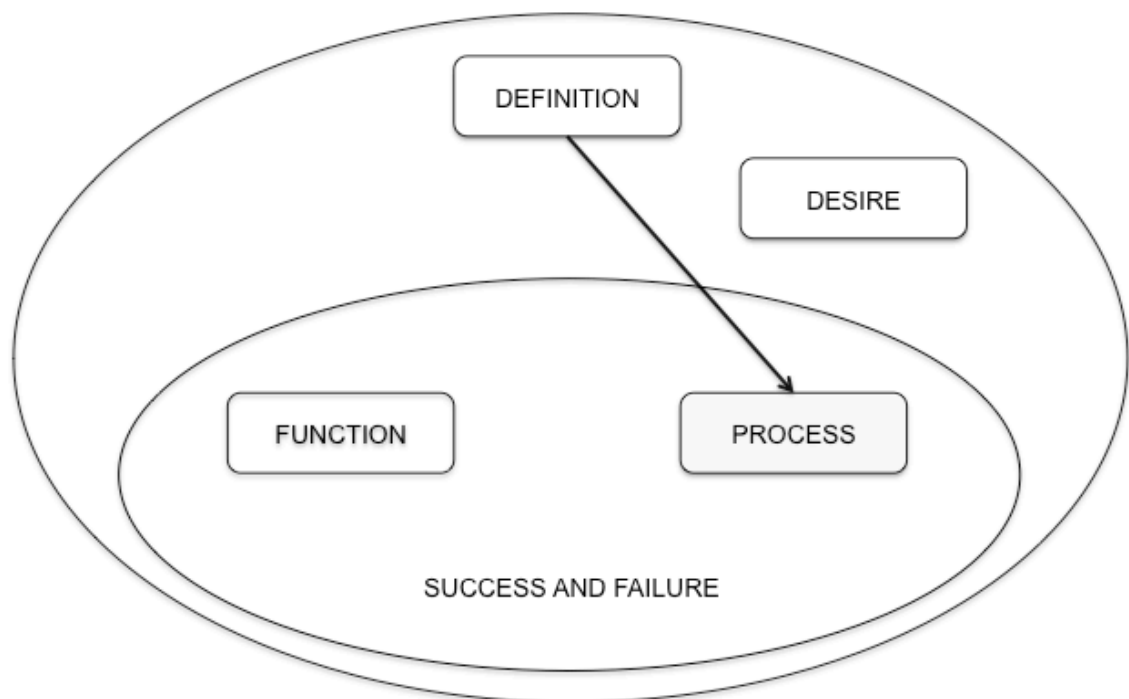
Having defined and named my themes, I moved to the final phase of my thematic analysis, producing the report. The report was the final outcome of my thematic analysis and is presented in Chapter Four.

4 Chapter Four: Findings

4.1 Introduction

Chapter Four critically examines the findings of my qualitative enquiry. Data were analysed using the six phases of thematic analysis (Braun and Clarke, 2006). The first five phases were described in the previous chapter, together with the process used for phase six. Chapter Four presents the outcome of phase six producing the report. The final thematic map is depicted in Figure Three:

Figure Three



Final thematic map of the meaning of sociality and friendship for persons with autism

The data informed my account of the meaning described by the sources of their lived experience of sociality and friendship that I have presented as themes. As shown in Figure Three, my analysis gave rise to five themes: desire, definition, function, process, and success and failure. The desire to be social, make

friends, and maintain friendships encompassed all other meanings that sources described of these phenomena. Success and failure in sociality, making friends, and maintaining friendship was described by many sources through reflection on their past experiences. Sources also frequently described the function of their sociality and friendship experiences in terms of how they had made them feel. When sources defined sociality, friends, and friendships this was often translated by them into the process of making and maintaining friendships, linking these two meanings.

In this chapter, I present the findings of my thematic analysis or what I have learned from my sources of their meaning of sociality and friendship. My findings provide the basis for the claims that I make in Chapter Five. The themes I defined and identified described the collective and individual meaning of these phenomena for the sources. I commence my analysis by tabulating the summary I presented in section 3.11.5 of each theme. In each table, I include a representative quotation for each claim I have made. I also cross-reference in the first column of Tables 1 to 5, the relevant sub-section in which I present my detailed analysis of each theme. Having used thirty-one online sources and ten autobiographical accounts published in books, it wasn't possible in the detailed analysis to cite all relevant sources as examples that supported the themes I had identified. Examples are, therefore, cited of four sources that best reflected the experience of sociality and friendship and described the collective meaning of these phenomena expressed by the sources as a whole. Statements and quotations from the transcribed data are also included that described the individual meaning that the sources made of sociality and friendship. I now present, in sections 4.2 to 4.6, my findings or what I have learned from my sources about their meaning of sociality and friendship that they described.

4.2 Theme One - Desire for sociality and friendship

The theme of desire for sociality and friendship of the sources is summarised in section 3.11.5 of my thesis. A representative quotation for each claim I have made in this summary is presented in Table 1:

Table 1 Theme One – Desire for sociality and friendship		
Sub-section	Claim	Representative quotation
4.2.1	Desired to be social and have friends and friendships	I think it's really important to have good friends and at least one good friend (EvieMay, YouTube, 2011c).
4.2.4	Assumed that persons with autism shared this desire	During your first semester, you will be the most social you will ever be during your college career because everyone is looking for friends in the beginning (Moss, 2014, p55).
4.2.1 and 4.2.2	Had socialised in the past, made friends, and maintained friendships	And I did have one friend who was my sort of cousin, who, you know, who I had sort of known since I was a baby basically and we used to play together (Catherine, Healthtalk, 2014d).
4.2.1 and 4.2.3	Socialised now and had friends and friendships	I've got a close group of friends on the Internet forum I go on (Alex, Healthtalk, 2010e).
4.2.3	Wanted to socialise in the future, make friends	I'll be able to meet people and make new friends focusing on making friends in those specific groups because that way I know I know they have a similar interest back (Victoria, YouTube, 2013).
4.2.4	Claimed to know the meaning that other persons with autism described of socialising and friendship	I think for many people on the autism spectrum and with Asperger's Syndrome, making friends is a challenge (Arman, YouTube, 2012a).

4.2.4	Wanted to support other persons with autism in achieving their desire for sociality and friendship	But the right kids can make your school experience much better. Now again these tips will be based on my own experience (Nathan, YouTube, 2014b).
4.2.1	Friendship desired with people	Make sure that you are meeting the right people and choosing the right people to be friends with (Victoria, YouTube, 2013).
4.2.1	Friendship desired with animals	In lieu of human friendship, many Aspergirls allow only four-legged, furry, or feathered friends into their hearts (Simone, 2010, p101) ⁵¹ .
4.2.1	Friendship desired with objects	Everyone was in their own groups of friends and there was me on my own; eventually, with the help of a rubber ball, I retreated into my own world because it was safer there. I could hear their name-calling but could carry on being in my own world with my ball (Pottage, 2008, p36).

I now present in sections 4.2.1 to 4.2.4 a detailed discussion of my data analysis of this theme.

4.2.1 Interest in socialising and friendship

Sources had posted a video blog, taken part in an online interview, or published an autobiographical account in a book that described their experience of sociality and friendship. These actions indicated the sources were interested in these phenomena (Pears, 2004; Ben, YouTube, 2012b; Kerry, YouTube, 2014c

⁵¹ Simone speaking of herself and other girls with AS.

Catherine, Healthtalk, 2014g). The title of some of the video blogs⁵² and autobiographical accounts in books included the theme of desire and signified the interest in the phenomenon of friendship that these sources had (Brown, 2008; Jarvis, 2008; Andrew, YouTube, 2011a; Victoria, YouTube, 2013). Victoria's (YouTube, 2013) video blog was entitled, "Asperger Syndrome – how to make and keep friends" and Lawson (2001) in her autobiography included a chapter entitled, "social understanding".

Some of the introductions to video blogs⁵³ and autobiographical accounts in books⁵⁴ also included references to sociality and friendship (McCabe, 2003; SillyGayBoy, YouTube; 2011b; Alex, YouTube, 2014a; Harris, 2015). In the introduction to her book, Moss (2014, p17) said in the first paragraph to her readers "I have a feeling that during this journey we will eventually become friends" and "I'll try my best to be a good friend to you by giving honest advice, listening and not judging you" (2014, p17). Victoria (YouTube, 2013) introduced her video blog by saying, "In this video I will be explaining how to make and keep friends".

Sources spoke or wrote about their interest in sociality and friendship (Lawson, 2001; Harvey, 2008; Mary, Healthtalk, 2010l; ErinClem, YouTube, 2012c). ErinClem (YouTube, 2012c) said, "So mm but yes I mean social situations they can be interesting". Harvey (2008) described his desire to socialise with the most popular students. Lawson (2001, p72) wrote of her friendships, "These friendships have been constructed over time and are very important to me". Other sources had had at times strong aspirations for a particular friend (Brown, 2008; Pears, 2008; Mary, Healthtalk, 2010l; Victoria, YouTube, 2013). Mary

⁵² Healthtalk interviews didn't have individual titles and interviews were posted on the website under generic titles such as "autism and friends".

⁵³ Introductions to Healthtalk interviews were presented in the form of text prior to the posting of the interviews. Healthtalk introductions were, therefore, not transcribed as they weren't the sources own words.

⁵⁴ The introductions in books weren't always written by the sources. In "Asperger syndrome and social relationships" (Edmonds and Beardson, 2008), one of the editors wrote the introductions and, therefore, this text didn't form part of the data set I transcribed. In other books, sources weren't writing exclusively about sociality and friendship and didn't, therefore, include a reference to these phenomena in their introduction (Lawson, 2001; Pears, 2004).

(Healthtalk, 2010I) said of her friend, “and I also was very possessive and quite sort of clingy because I didn’t like it when anyone else would start talking to her”.

Socialising and friendship was desired predominantly with people (James, Healthtalk, 2010a; Sillygayboy, YouTube, 2011b; Richard, Healthtalk, 2014a; Sam Healthtalk, 2014c). Alex (Healthtalk, 2010e) said, “The majority of my friendships are always net based. They’re people... you know”. Four sources desired to socialise with objects (Pottage, 2008; Debumaiya, YouTube, 2010; Tony, YouTube, 2012b; Harris, 2015) or with animals (Lawson, 2001; Pears, 2004; Pottage, 2008; Simone, 2010) and regarded them as friends. Pottage (2008, p36) described her experience of being at school by saying she was “longing for home time and to be with my greatest friend, who was called Rufus, he was a large golden Labrador dog”. Tony (Tony, YouTube, 2012b) described his plastic model figures as his friends and Harris (2015, p27) stated:

The difficulty I experienced in developing relationships with other people did, in some strange way, give me the compensatory gift of a connection with the natural world. The very capacity I lacked in making friends came back to me a hundredfold in forging relationships with the world of matter.

4.2.2 Past experiences of socialising and friendship

Many sources reflected on their past experiences of socialising and friendship in terms of when they had socialised and had made friends (Brown, 2008; Debumaiya, YouTube, 2010; James, Healthtalk, 2010a; Harris, 2015). Harris (2015, p14) said, “That day I made a friend and what a friend she was!” Several sources described their experiences in school (Mary, Healthtalk, 2010I; Ben, YouTube, 2012b; Victoria, YouTube, 2013; Sam, Healthtalk, 2014c). Victoria (YouTube, 2013) talked about what she had learned through her friendship experiences at school, and Mary (Healthtalk, 2010I) stated, “When I started secondary school, I actually made a friend on the first day”.

Various sources reflected on different past experiences of socialising, making friends, and maintaining friendships (Brown, 2008; Simon, Healthtalk, 2010i; Andrew, YouTube, 2011a; Harris, 2015). Alex (YouTube, 2014a) spoke of his website Wrongplanet.net, “I created this website to find others like me”. Andrew (YouTube, 2011a) described his experiences of trying to make friends having moved to a new city. Brown (2008) said she had wanted to socialise as a teenager and a young adult. Harris (2015) described how as a child she had wanted to socialise with other people. Nathan (YouTube, 2014b) described how he had met some of his best friends at his drama group and Kerry (YouTube, 2014c) stated, “I have had different types of friendships over the course of several years”.

4.2.3 Current and future experiences of socialising and friendship

Throughout video blogs, online interviews, and autobiographical accounts in books, sources frequently referred to socialising, having friends, and to maintaining friendships (Lawson, 2001; Moss, 2014; Nathan, YouTube, 2014b; Kerry, YouTube, 2014c). Richard (Healthtalk, 2014b) described that the “friends I mentioned earlier are the ones I live with. I have other friends who I’ve known for longer who don’t live with me”. In the video blogs and interviews, some sources stated they had friends at present (Mark, Healthtalk, 2010d; Oliver and Susie, Healthtalk, 2010f; Richard, Healthtalk, 2014b; Sam, Healthtalk, 2014f). Arman (YouTube, 2012a) stated, “I mean I still go social dancing and I would say a couple of people there I have met there are my friends”. Whilst sources described a desire to have friends, some stated they didn’t have the need for friends all the time (Lawson, 2001; McCabe, 2003; Harvey, 2008; Arman, YouTube, 2012a). Simone (2010, p95) said of herself and others with AS, “We love our alone time” and went on to state, “But at the same time, most of us also crave companionship and fun”.

Three sources also aspired to socialise, make new friends and maintain friendships in the future⁵⁵ (Harvey, 2008; Victoria, YouTube 2013; Kerry YouTube, 2014a). Harvey (2008, p48) stated:

In my own case, I do not know what the likely outcome from tomorrow will be with friends and relationships: it depends on who I meet on life's journey, what I can cope with myself, and what the people I meet actually want from me and if they feel comfortable around me.

4.2.4 Supporting the sociality and friendships of persons with autism

A number of sources⁵⁶ claimed to know that other persons with autism shared their desire to socialise, make friends, and maintain friendships (Simone, 2010; Moss, 2014; Alex, YouTube, 2014a; Nathan, YouTube, 2014b). Simone (2010) said that girls with AS wanted companionship. Kerry (YouTube, 2014c) spoke about how he thought friendship was “something that’s very important mm [to] those of us with Asperger Syndrome”.

Some sources wanted to help other persons with autism in fulfilling this perceived need by providing support and encouragement as to how to do so (Andrew, YouTube, 2011a; Moss, 2014; Alex, YouTube 2014a; Nathan, YouTube, 2014b). Harris (2015) described the aim of her book as by examining her own life, she could give hope to other people with autism coping with a range of issues including social confusion. Simone (2010, p103) said, “If you want more friends, *do something about it*. Don’t give up” (author’s italics).

Several sources⁵⁷ stated why they had posted a video blog or written about sociality and friendship. The reason was to support other persons with autism in socialising, making friends, and maintaining friendships (Simone, 2010;

⁵⁵ Many sources were reflective in that they described their past socialising and friendship experiences.

⁵⁶ The Healthtalk sources only described their own meaning of sociality and friendship and not those of other persons with autism.

⁵⁷ Healthtalk sources didn’t state why they were talking about socialising and friendship.

Andrew, YouTube, 2011; Victoria, YouTube, 2013; Alex, YouTube, 2014a). Victoria (YouTube, 2013) spoke about how she had made her video blog to explain to Aspies⁵⁸ "how to make friends and keep friends".

Some sources also felt their video blogs and autobiographical accounts published in books were supportive as they directed viewers and readers to other resources (Lawson, 2001; Victoria, YouTube, 2013; Moss, 2014; Alex, YouTube, 2014a). Alex (YouTube, 2014a) asked, "Where can teens go what can they do to make friends and practice socialising? Well the first place that I had recommended is wrongplanet.net". Simone (2010, p236) recommended five websites and wrote that www.aspie.com included "articles addressing Aspie relationships". Several sources who posted video blogs invited feedback from viewers (EvieMay, YouTube, 2011c; Victoria, YouTube, 2013; Nathan, YouTube, 2014b; Kerry, YouTube, 2014c). EvieMay (YouTube, 2011c) closed her video blog by saying, "Please rate, comment and subscribe".

4.3 Themes Two - Definition of sociality and friendship

Section 3.11.5 summarises my second theme, the definition of sociality and friendship. A representative quotation for each claim I have made in this summary is presented in Table 2 below:

Table 2 Theme Two – Definition of sociality and friendship		
Sub-section	Claim	Representative quotation
4.3.1	The size of social and friendship groups	I can be with a large group or a small group of people (Arman, YouTube, 2012a).
4.3.3	The sharing of activities	I joined a lot of clubs. I was in a band I played music (Alex, YouTube, 2014a).
4.3.3	The sharing of	I'll be working and guest speaking

⁵⁸ Aspies is an abbreviated term for persons with AS.

	experiences	and involved in the university I'll get that opportunity to go and speak to people and you know make new friends (Kerry, YouTube, 2014c).
4.3.2	The sharing of physical space	I became friendly with a girl in the year above me, who told that I could come round to her house whenever I liked. So, taking her at her word. I spent most of my free time there (Brown, 2008, p67).
4.3.2	The sharing of virtual environments	Most of them are my Facebook friends (Debumaiya, YouTube, 2010).
4.3.4	Different people as friends	It's like people who are older than me are, they're kind of more, I find it easier to relate to them because I'm very old and young at the same time (Mary, Healthtalk, 2010b).
4.3.5	Desirable personal qualities in people	To me, a friend is, you know, someone you can trust (Simon, Healthtalk, 2010K).

I now present in sections 4.3.1 to 4.3.5 a detailed discussion of my data analysis of this theme.

4.3.1 Social and friendship groups

Some sources defined social and friendship groups in terms of having one friend (Brown, 2008; Mary, Healthtalk, 2010i; Sillygayboy, YouTube, 2011b; Sam, Healthtalk, 2014f). Arman (YouTube, 2012a) reflected, "You know for me I have I would say one good friend at the moment". Other sources said they had a few friends (Debumaiya, YouTube, 2010; Andrew, YouTube, 2011a; Erinclem YouTube, 2012c; Moss, 2014). Debumaiya (YouTube, 2010) said, "Growing up I did have a few friends". Two sources stated they had a large group of friends

(Alex, Healthtalk, 2010e; Arman, YouTube, 2012a) and some reflected on the right number of friends for them (Simone, 2010; Arman, YouTube, 2012a; Moss, 2014; Sam, Healthtalk, 2014f). Erinclem (YouTube, 2012c) reflected, “That’s why I have those few friends that are really awesome and understand me and support me”. Simone (2010), EvieMay (YouTube, 2011c) and Sam (Healthtalk, 2014f) talked about how it was important to have one good friend. Sam (Healthtalk, 2014f) stated, “and quite simply the benefit that brings is worth more than having twenty or thirty friends who you can socialise with and spend time with”. Other sources (Nathan, YouTube, 2014b; Erinclem, YouTube, 2012c) described how it was better to have a few close friends than a larger number who didn’t really understand you. Nathan (YouTube, 2014b) said:

For the longest time I thought that because I didn't have a lot of friends that it made me lesser. Eventually I started to realise that you know what those cool kids are popular kids can brag about how many friends they have all day. But it's much better to use your time and energy to find just a few really true ones.

4.3.2 Physical and virtual environments

The definition of sociality and friendship was seen by some sources as including the sharing of the same physical space (Pottage, 2008; Victoria, YouTube, 2013; Nathan, YouTube, 2014b; Richard, Healthtalk, 2014b). Alex (Healthtalk, 2010e) said, “Obviously there’s people that go to the same day service as me and when we go out and do social things. We all get together and we all talk and stuff”.

Different sources reflected on socialising and making friends in a variety of environments. Andrew (YouTube, 2011a) and Debumaiya (YouTube, 2010) described the people they worked with as friends and several sources (Harvey, 2008; Moss, 2014; Nathan, YouTube, 2014b; Richard Healthtalk 2014b) spoke about their friends in college. Moss (2014, p68) said, “I usually explain my social life at college by saying that I probably know at least 100 people from different organisations, retreats, and areas of campus, but I truly consider myself friends with one or two people”. Pears, (2004), Ben (YouTube, 2012b)

and Victoria (YouTube, 2013) talked about their friends at school. Pottage (2008, p36) reflected, “At school I had two female friends who took me under their wings”. Arman (YouTube, 2012a) and Alex (YouTube, 2014a) described the friends they had made at the groups they had joined.

A number of sources defined these phenomena through participating in virtual spaces, that is online forums and social media (Harvey, 2008; Alex, Healthtalk, 2010e; Evie May, YouTube, 2011c; Moss, 2014). Like physical spaces, different sources defined socialising and friendship in a variety of environments. Debumaiya (YouTube, 2010) and Victoria (YouTube, 2013) included Facebook contacts in their definition of friends. Moss (2014, p120) said, “I’ll be honest: Facebook is great”. Simone (2008, p99) stated, “Facebook, Twitter and other Internet tools can be extremely helpful in maintaining at least some semblance of a social life” and went on to say, “It is possible to conduct fairly meaningful relationships online”. Alex (YouTube, 2014c) had created his own social space and friendship group through his website Wrongplant.net (Wrongplanet, 2012) so he could socialise and make friends. Arman (YouTube, 2012a) had his own website for this purpose empowerautismnow.com (Empowerautism, 2016).

4.3.3 Sharing interests and activities

Socialising and friendship were also defined by several sources as involving the sharing of a common interest with a person or number of people (Lawson, 2001; Brown, 2008; Victoria, YouTube, 2013; Nathan, YouTube, 2014a). Simone (2010, p87) said, “If you are genuine and pursue your own interests, that is how you will connect with your soul mates – whether friends, colleagues or romantic partners”. Groups were often seen as providing the opportunity to socialise and to make friends (Harvey, 2008; Debumaiya, YouTube, 2010; Arman, YouTube, 2012a; Nathan, YouTube, 2014a). Sources participated in various activities. Alex (YouTube, 2014c) joined a drama and speech group and a band reflecting his interests. Victoria (YouTube, 2013) joined music groups, James (Healthtalk, 2010a) described how he did a lot of coaching and Sillygayboy (YouTube, 2011b) took acting classes. Pears (2004, p13) said of her special interests:

Teenagers of all shapes, sizes and colours would welcome me into their little circles. We would sit around painting, sculpting, writing and making music. At night we would stay up late, watching horror films, then laugh and joke, telling wild tales to one another as friends.

Several sources also participated in informal activities. This included dining with other people (Simon, Healthtalk 2010i; Victoria, YouTube, 2013; Moss, 2014; Richard, Healthtalk, 2014b) and conversation (McCabe, 2003; Alex, Healthtalk, 2010e; Oliver and Susie, Healthtalk, 2010f; Sillygayboy, YouTube, 2011). Moss (2014, p70) said of College that “Dining halls are often social spaces” and Richard (Healthtalk, 2014b) stated that he liked “ordering takeaway” with his friends. Harris (2015, p13) described how as a child she used to take toys and books to school that she viewed as “conversation starters” with other children. Pears (2004, p26) said of her interest in a conversation, “I want to be with girls my own age who I can make friends with: normal, talky girls. Girls who talk like me and listen to pop music!”

4.3.4 Different people as friends

A number of sources described their experiences of socialising and making friends with people of a similar age (Pears, 2004; Moss, 2014; Richard, Healthtalk, 2014b; Sam, Healthtalk, 2014f). Harris (2015, p41) stated about school, “Motivated as I was to find a place of belonging among my peers, I did not give up but started to talk to and hang around a group of “popular” girls”. Acquaintances were also viewed as friends by some sources (Pottage, 2008; Debumaiya, YouTube, 2010; Arman, YouTube, 2012a). Arman (YouTube, 2012a) said, “For me I have many acquaintances but allowing myself to get close to others is a challenge”. Family members were also regarded by a few sources as friends (Harvey, 2008; Simone, 2010). Harvey (2008, p47) wrote, “My father, mother and brother have all been very loyal and supportive to me throughout my life, and therefore I see them as friends like any other type of friend. As well as parents and brother”.

Some sources described that their definition of friendship was with younger or older people (Brown, 2008; Simone, 2010; Mary, Healthtalk, 2010b;

Sillygayboy, 2011b). Simone (2010, p96) said of herself (and other girls with AS):

We don't cultivate or maintain "appropriate peer relationships." When we're younger we may be attracted to older people because of our intellectual maturity and hyperlexia, but as we get older, we may feel more comfortable with younger people because we don't mature emotionally. As adults we find people our own age boring and lacking in similar interests.

Several sources talked about how they defined sociality and friendship through being with other persons with the label of autism (Harvey, 2008; Ian, Healthtalk, 2010c; Oliver and Susie, Healthtalk, 2010f; Moss, 2014). Ian (Healthtalk, 2010c) described how he found it easier to make friends with persons with autism. He stated, "All my friends who are autistic talk very similarly, you know what I mean we always have a good conversation and we think the same".

4.3.5 Personal qualities

Various sources also defined sociality and friendship through their understanding of desirable qualities in people who they wanted to socialise, make friends, and maintain friendships with. These sources understood the qualities in persons that made good friends for them (Lawson, 2001; Oliver and Susie, Healthtalk, 2010f; Simon, Healthtalk, 2010k; Victoria, YouTube, 2013). Lawson (2001, p71) said, "I value honesty, commitment and trustworthiness, so, I relate to others with these qualities".

A number of sources described their understanding of the personal qualities in people that didn't make good friends for them (Lawson, 2001; Brown, 2008; Jarvis, 2008; Victoria, YouTube, 2013). McCabe (2003,p45) stated, "I cannot be close to someone that lies to me; there is no foundation for the relationship". Ian (Healthtalk, 2010c) and Oliver (Oliver and Susie, Healthtalk, 2010f) described how they found it easier to make friends with other persons with autism because they had similar personalities. Harris (2015) described finding the

strength from being with a group of girls with autism that enabled her not to feel she had to conform with PNT teenagers.

Several sources stated that they had control and influence in their choice of whom they socialised with and who were their friends (Arman, YouTube, 2012a; Victoria, YouTube, 2013; Moss, 2014; Nathan, YouTube, 2014b). Moss (2014, p70) explained how she used disclosing her diagnosis as a way of identifying people who were good friends for her and stated, “Those who matter don’t mind, and those who mind don’t matter”. In contrast, some sources described that at times they felt they didn’t have a choice in who they were friends with (Brown, 2008; Pottage, 2008; Mary, Healthtalk, 2010l; Sam, Healthtalk, 2014c). Mary (Healthtalk, 2010l) talked about how on occasions a girl told her she didn’t want to be friends with her anymore. Pottage (2008, p36) said of being talked about behind her back and to her face by friends at school, “I took it because they were the only friends that I had and I did not know how to make friends at playtime”.

4.4 Theme Three - Function of sociality and friendship

In section 3.11.5, I presented the third theme that I have identified, the function of sociality and friendship. A representative quotation for each claim I have made in this summary is presented in Table 3 below:

Table 3 Theme Three – Function of sociality and friendship		
Sub-section	Claim	Representative quotation
4.4.1	Made an emotional connection with someone	Some find the growing sense of community among those with Asperger’s means it is possible to have several friends that are also on the spectrum. It feels really good to talk to those who understand, to whom you do not constantly have to explain yourself (Simone, 2010,

		p100).
4.4.1	Did not make an emotional connection with someone	I have always found that sort of level of emotional detachment, you know, yes I really like you as a person, but if you fell off the face of the earth tomorrow, would I be upset? I am not terribly sure I would be (Mark, Healthtalk, 2010d).
4.4.2	Removed a negative emotional state	And so that was probably, probably the reason I enjoyed university, was because I actually managed to meet someone who actually I could connect with and be friends with (Sam, Healthtalk, 2014f).
4.4.2	Resulted in a positive emotional state	Giddy with excitement, we ran up and down the length of the room waving our arms and groaning like zombies, getting tangled up in the woolen cobwebs and laughing all the while with the sheer joy of running amok! (Harris, 2015, p16).
4.4.1, 4.4.2 and 4.4.3	Reflected on how past experiences had made them feel	Imagine going to school every day and not having a single friend. I was very depressed I didn't enjoy life (Ben, YouTube, 2012b).
4.4.3	More instances of negative emotional states than positive ones	It wasn't particularly easy, school, in fact I hated school. It was a lot of stress. I just... I certainly worked hard at it and I certainly made a lot of effort towards it, but I dreaded going most days (Sam, Healthtalk, 2014c).

A detailed discussion of my data analysis of this theme is now presented in sections 4.4.1 to 4.4.3.

4.4.1 Emotional connection

Several sources described whether or not they had been able to make an emotional connection with someone through socialising and friendship. Some sources stated that at times they had been unable to do so (Jarvis, 2008; Mark, Healthtalk, 2010d, Simon, Healthtalk, 2010k; Richard, Healthtalk, 2014e). Sam (Healthtalk, 2014c) of his experiences at school said, “I didn’t make new friends. The friends I did make eventually I felt weren’t really interested in me at all to be honest. They just seemed, I don’t know, very distant”. Other sources stated they had occasionally formed a very strong attachment to someone (Brown, 2008; Pottage, 2008; Mary, Healthtalk, 2010l; Victoria, YouTube, 2013). Lawson (2001, p71) said of her experiences, “I have tended to form over-attachments or no attachment at all. Getting the balance ‘right’ is rather a difficult task when one’s sense of self and of other is confusing, scattered, fragmented and incomplete!”

4.4.2 Positive emotional states

Socialising and friendship frequently enabled sources to experience positive emotional states (Brown, 2008; James, Healthtalk, 2010a; Erinclem, YouTube, 2012c; Kerry, YouTube, 2014c). Different sources used various adjectives to describe how they felt about socialising and friendship experiences that evoked positive emotional states, e.g., happy (Simone, 2010; Harris, 2015), awesome (Erinclem, YouTube, 2012c), joy (Simone, 2010), amazing (Moss, 2014), love (McCabe, 2003; Brown, 2008; Erinclem, YouTube, 2012c), and great (Lawson, 2001; Moss, 2014; Kerry, YouTube, 2014c). Erinclem (YouTube, 2012c) said of her friends, “I swear I love my friends. They are awesome”. Brown (2008, p71) described how she was “quite happy with having my best friend, who is also my partner, my family and the one good friend I do have”. Ben (YouTube, 2012b) stated, “I’ve got friends now. I’m just happy to have friends”. McCabe (2003, p44) wrote, “Social life can be fun”.

Not having negative social or friendship experience was regarded positively by a few sources (Jarvis, 2008; Debumaiya, YouTube, 2010; Moss, 2014; Sam,

Healthtalk, 2014c). Sam (Healthtalk, 2014c) said of his childhood, “I thankfully wasn’t bullied which was probably a very, I’d say lucky. I was slightly bullied on my paper round, but not actually in school, so it wasn’t so bad”. Andrew (YouTube, 2011a) stated, “If I was lucky I would have maybe two three friends by the end of the semester”. Sillygayboy (YouTube, 2011b) recounted his friendship experiences and said he felt lucky to have had a few friends. Debumaiya (YouTube, 2010) shared this view and reflected, “I would have like one or two friends that would waltz in and out of my life. A lot of us well we grew up without having friends. And well I consider myself to be one of the lucky ones on that matter”.

4.4.3 Negative emotional states

Many of the sources described the negative feelings that they experienced from not having friends, finding it difficult to socialise and make friends, or from not being able to maintain friendships. Many more instances of negative emotional states were described by the sources than positive ones (Simone, 2010; Mary, Healthtalk, 2010l; Sam, Healthtalk, 2014c; Harris, 2015). Lawson (2001, p88) described, “Social phobia and other fears and phobias may dominate my existence” and Andrew (YouTube, 2011a) that “One thing I’ve found in order to make friends in a big city it seemed overwhelming”. Harris (2015, p4) stated that:

For children on the autism spectrum, the playground is a noisy, chaotic, nerve jangling environment with every changing social rules that are totally lost on them – and so it was for me.

A range of adjectives was used by different sources to describe how not having friends or how being treated badly by people they regarded as friends made them feel, e.g., upset (Pears, 2004; Mary, Healthtalk, 2010l; Harris, 2015), depressed (Brown, 2008; Jarvis, 2008; Ben, YouTube, 2012b; Victoria, YouTube, 2013), lonely (Pottage, 2008; Simone, 2010; Erinclem, YouTube, 2012c; Harris, 2015), scared (Simon, Healthtalk, 2010k; Sillygayboy, YouTube, 2011b; Moss, 2014; Catherine, Healthtalk, 2014g), misunderstood (Lawson,

2001; Mary, Healthtalk, 2010l; Ben, YouTube, 2012b; Victoria, YouTube, 2013), and anxious (Pottage, 2008; Ian, Healthtalk, 2010g; Moss, 2014; Catherine, Healthtalk, 2014g).⁵⁹ Victoria (YouTube, 2013) described occasions of trying to make a friend and failing by saying, “they were really depressing” and Jarvis (2008, p28) said, “I have been lonely for periods of my adult life as a consequence of not being proactive about socialising to make friends”. Of her sociality and friendship experiences at school, Harris (2015, p43) stated:

At night, after everyone was asleep, I would lie in bed, turning the contents of these and other upsetting encounters and conversations over and over in my head—as Asperger girls are prone to do. Each recollection, no matter how many times it had been recalled, brought fresh waves of emotional distress as I agonised over the details.

A number of sources talked about how they had been bullied at school (Pears, 2004; Sillygayboy, YouTube, 2011b; Ben, YouTube, 2012b; Catherine, YouTube, 2014d) and the negative emotional states this resulted in. Ben (YouTube, 2012) described being bullied at school and said, “I actually did not want to live I actually did not want to live at that time”. Simone (2010, p96) stated:

Once you’ve been bullied, it gives you a glimpse into the darker side of human nature that other people may rarely, if ever, see. That is something you never quite forget, even if you learn to get along with people and see their good side later in life. It can prevent you from ever getting truly close to people, for you come to believe that what constitutes popularity is not something of any deep or lasting value.

Several sources described how they felt isolated in social settings when they tried to socialize (Pears, 2004; Simone, 2010; Erinclem, YouTube, 2012c; Catherine, Healthtalk, 2014g). Pottage said (2008, p35), “Always being on the outside looking in on people but never feeling a part of what is going on must be

⁵⁹ The authors of books used a greater range of adjectives than the online sources to describe their negative emotions, e.g., no hope, miserable, alienated, embarrassed, suicidal, frustrated, insecure, ashamed, flawed, overwhelmed, afraid, and vulnerable.

the loneliest place on the planet”. McCabe (2003, p144) said of his experience at college:

I found myself sometimes going entire weekends and days off without leaving my dorm or talking to anyone. It eventually drove me crazy. I'd get really sad, anxious, or just tired because I had nothing to do or nowhere to go or nobody to see. This my friends, is what isolation feels like.

Some sources described how they felt about trying to socialise and make friends in the future (Jarvis, 2008; Victoria, YouTube, 2013; Kerry, YouTube, 2014c). Victoria (YouTube, 2013) thought that joining groups that shared her interests would make her feel safe and not judged. Kerry (YouTube, 2013) thought that making new friends “isn’t going to be an easy thing for somebody like me with Asperger Syndrome”.

4.5 Theme Four – Process of sociality and friendship

In section 3.11.5, I described the fourth theme that I have identified, the process of sociality and friendship. As shown in Figure Three, “Final thematic map of the meaning of sociality and friendship for persons with autism”, the theme definition is linked to that of the process of sociality and friendship. When sources defined sociality and friendship, this was also the means by which they socialised, made friends, and maintained friendships. A detailed description of the meaning described by these sources of the use of physical and virtual spaces in the process of sociality and friendships is, therefore, included in section 4.3.2, of sharing personal interests in section 4.3.3, and of different people as friends in section 4.3.4. Section 4.5.1 presents the remainder of the meaning of Theme Four, i.e., the difficulties described by some sources in accessing opportunities to socialise, make friends, and maintain friendships.

A representative quotation for the claim I have made in my summary of this theme is presented in Table 4:

Table 4 Theme Four – Process of sociality and friendship		
Sub-section	Claim	Representative quotation
4.5.1	Described what on occasions prevented them from socialising, making friends, and maintaining friendships	In terms of conversation, generally, first its very hard to think of anything to say in the first place, although if you know you have a common interest that may help. Second, it can be difficult to concentrate if the conversation is based purely on social chit chat, or a subject outside your experience (Brown, 2008, p62).

I now present in section 4.5.1 a detailed discussion of my data analysis of this aspect of Theme Four.

4.5.1 Difficulties socialising, making friends, & maintaining friendships

A number of sources described what they claimed had prevented them from accessing opportunities to socialise, make friends, and maintain friendships. The lack of shared interests with other persons including with the PNT was highlighted by some sources as a reason why they didn't socialise and consequently didn't make friends (Jarvis, 2008; Mary, Healthtalk, 2010b; Sillygayboy, YouTube, 2011b; Richard, Healthtalk, 2014a). Harvey (2008, p44) said, "Unfortunately most hobbies taken up by people with AS are the sort which can be and are largely done alone, so the opportunities to meet others are substantially reduced". Jarvis (2008, p29) stated, "I know I bored people by talking at length on subjects that they weren't interested in, and this would hinder my attempts to develop friendships".

Many sources reflected on how either their social approaches were misunderstood by the PNT or that they didn't understand those made to them (Pears, 2004; Brown, 2008; Ben, YouTube, 2012b; Victoria, YouTube, 2013). Ian (Healthtalk, 2010c) and Mary (Healthtalk, 2010l) talked about how it was

difficult to adapt to the PNT. Erinclem (YouTube, 2012c) and Harris (2015) described how they found it difficult to read the social cues of the PNT. Debumaiya (YouTube, 2010) said of himself and other persons with autism, "We have trouble understanding social cues or have difficulties expressing ourselves". Richard (Healthtalk, 2014e) described how he could "read somebody else's body language if I remember. I would have to remember and say, "Ah yes. I think that means such and such".

Various sources described a lack of acceptance by the PNT (Jarvis, 2008; Simone, 2010; Victoria, YouTube, 2013; Nathan, YouTube, 2014b). Victoria (YouTube, 2013) said, "I should have spent my time focusing on the people who accepted me and made time for me rather than focusing on the people who didn't and who I wanted to please so much". Debumaiya (YouTube, 2010) stated, "I guess a lot of us growing up were considered to be outcasts and always wanted to have friends but had difficulty doing so". Several sources were surprised when they felt accepted by the PNT (Pears, 2004; James, Healthtalk, 2010a; Alex, YouTube, 2014a, Harris, 2015). James (Healthtalk, 2010a) described how he was surprised he had been made Prom King and said, "It makes people sit up and take notice a bit about that, that idea that thinking happens, the idea that people with Asperger Syndrome are like capable of making friends socially".

A number of sources thought that being a person with autism had made it difficult for them to socialise, make friends, or maintain friendships or would do in the future (Lawson, 2001; Debumaiya, YouTube, 2010; Simon, Healthtalk, 2010k; Arman, YouTube, 2011). Simon (Healthtalk, 2010k) said that because of his autism making friends was difficult "because part, part of autism is we have a very sort of strange sort of social system". Jarvis (2008, p31) stated, "I can converse with neurotypical people for several hours without too much difficulty. If I have to talk for much longer than this, I find that I get tired mentally".

4.6 Theme Five - Success and failure in sociality and friendship

In section 3.11.5, I presented the fifth theme that I have identified, success and failure in sociality and friendship. A representative quotation for each claim I have made in this summary is presented in Table 5 below:

Table 5 Theme Five – Success and failure in sociality and friendship		
Sub-section	Claim	Representative quotation
4.6.1	Sources described their successful experiences of socialising, making friends, and maintaining friendships	I did have a few good friends as I was growing up (Brown, 2008, p67).
4.6.3	Sources described their failed experiences of socialising, making friends, and maintaining friendships	I didn't sort of have friends, I mean say primary school, I just felt really left out, and I didn't really have any friends. (Catherine, Healthtalk, 2014d).
4.6.3	More instances of failing to socialise, making friends, and maintaining friendships	As a child and as an adult, I lived my life with the assumption that I was normal and I tried to fit in. At school this led me to play the role of 'joker'. I tried to be funny to be part of a group. But this strategy rarely helped me make friends and only served to damage my fragile sense of self-worth (Jarvis, 2008 p28)
4.6.4	Claimed to know their experiences were shared with other persons with autism	I've read countless times about Aspergers that they have a hard time either making the friend in the first place and if they do

		make a friend that they have a hard time keeping that friend (Sillygayboy, YouTube, 2011b)
4.6.1	Strategies used to increase success in socialising, making friends, and maintaining friendships	I was fortunate to be able to partake in a social group for a short time in my early twenties and we all picked up useful social skills by exchanging ideas and information about how to react appropriately, rules about spacing in crowds and other such skills (Harvey, 2008, p44).
4.6.1	Strategies had increased their success in socialising, making friends and maintaining friendships	I learned that listening and asking the right questions to show an interest in the other person was a great way to make new friends (Jarvis, 2008, p30).
4.6.2	Recommendations to other persons with autism to increase success	While you may want to run straight home after school, joining extracurricular activities might put you in touch with other people with similar interests; you may find another Aspergirl in the drama or science club. (Simone, 2010, p32).
4.6.3 and 4.6.4	Comparison of degree of success in socialising and friendship experiences to that of the PNT	Socially speaking, I had bitten off more than I could chew and had been growing increasingly exhausted by my attempts to emulate their confusing and fickle ways (Harris, 2015, p43).

I now present in sections 4.6.1 to 4.6.4 a detailed discussion of my data analysis of this theme.

4.6.1 Success in socialising and friendship

Different sources recounted past experiences of socialising and friendship when they felt they had been successful in making friends or maintaining friendships (McCabe, 2003; Ian, Healthtalk, 2010c; Ben, YouTube, 2012b; Sam, Healthtalk, 2014f). Several sources described how they had encountered people in the past who were willing to socialise with them and develop a friendship. Moss (2014, p123) reflected on her experience of being homesick at college and said, “My friend remembers me crying about how much I hated our college town”. Two sources anticipated future successes for themselves in socialising, making friends, and maintaining friendships (Victoria, YouTube, 2013; Kerry, YouTube, 2014c).

Whilst sources generally described successful friendship experiences with people, four sources talked about the success they had at making friends with objects (Pottage, 2008; Debumaiya, YouTube, 2010; Tony, YouTube, 2012b; Harris, 2015). Tony (YouTube, 2012b) said of his friendship with his toy soldiers, “They keep me company. I don’t feel lonely with them around”. Four sources described the success they had experienced with animals as friends (Lawson, 2001; Pears, 2004; Pottage, 2008; Simone, 2010). Pottage (2008, p36) described Rufus, her golden Labrador as her “greatest friend”.

Some sources described how they had developed strategies for themselves with the aim of being more successful at socialising, making friends, and maintaining friendships. Strategies included identifying opportunities to socialise and make friends (Simone, 2010; Victoria, YouTube, 2013; Kerry, YouTube, 2014c; Harris, 2015). Stephen (Healthtalk, 2010m) said:

So strategies, yes, you do learn strategies from an early age I think and the problem is with people probably on the spectrum is that you have got a lot of information that you need to store away because you have to remember the strategies for those situations because it doesn’t come naturally so you have to pull that out of your little film cabinet that you have got in your head and play it quite quickly so you know what to do. It is not inherent really, so yes, there are lots of strategies I think that you learn. I think it just takes time.

A number of sources described how they had joined clubs that shared their special interests (Sillygayboy, YouTube, 2011b; Victoria, YouTube, 2013; Moss, 2014; Alex, YouTube, 2014a). Nathan (YouTube, 2014b) described how in the drama and speech group that he joined he had “met some of the best friends that I’ve ever had in those programmes many of which I’m still friends with in college”. Harris (2015, p15) formed her own club at school and reflected, “Murmurs of conspiratorial glee ran through the ranks of girls who had associated themselves with the “Haunted House Club.” Arman (YouTube, 2012a) ran a club for persons with autism and stated, “I consider all the people that come to my groups my autism groups that I run to be friends”.

Many persons with autism in my study talked about how they wanted to improve their PNT social skills (Jarvis, 2008; James, Healthtalk, 2010a; Oliver and Susie, Healthtalk, 2010f; Alex, YouTube, 2014a). Moss (2014, p150) wrote, “If I’m unsure of how to act or what to do, I ask my parents. Back when I was younger we’d script social scenarios so I would know what to do”. Pottage (2008) recorded TV programmes and watched them to try and identify emotions and non-verbal cues. Harris (2015) practised her social skills as a child through playing at tea parties. Simone (2010) described how the social group she attended provided her with useful tips as to how to act appropriately in social environments. Richard (Healthtalk, 2014e) said, “When I read that most people do have a need for eye contact I trained myself to do it”. Erinclém (YouTube 2012c) stated how she had asked her friends to answer questions on social situations to improve her understanding. Jarvis (2008, p30) said, “The move from unconsciously incompetent to consciously competent with respect to social skills can be a very slow process of learning through repeated failure”. Pottage (2008, p36) stated, “I have also learned that it’s OK to sit on the sidelines and watch and try to learn social cues and habits as this does not come at all naturally to me”.

Several sources described PNT personal qualities that they felt they needed to develop to facilitate them in socialising, making friends, and maintaining friendships (Jarvis, 2008; Victoria, YouTube, 2013; Richard, Healthtalk, 2014e; Harris, 2015). Victoria (YouTube, 2013) talked about how it’s important to think

about how you present yourself to someone and to make them feel comfortable so that they want to talk to you. Lawson (2001) and Richard (Healthtalk, 2014e) described how they had tried to learn about empathy. Richard (Healthtalk, 2014e) stated, “I came to the conclusion that it was not right for a husband and father not to have any empathy and that I would therefore work on learning to have empathy”. Jarvis (2008) said that after realising he was boring people he acquired some social awareness and only talked for a few minutes on a particular topic. In addition, he practised softening his facial expressions in a mirror. Harris (2015, p71) described how she went to great lengths to mirror phrases, gestures and accents of the people she was with to the extent that “Like a chameleon, I had taken on the colour of my surroundings, blending in to hide my social vulnerabilities”.

Some sources attributed their success in socialising, making friends and maintaining friendship to the strategies they had used. Jarvis (2008, p30) stated that being polite “had been key to my increasing success in making friends”. Oliver (Oliver and Susie, Healthtalk, 2010f) explained he had “learnt to make conversation with people” and “to deal with being in social situations” and this explained why Susie said people found him quite friendly. Harris (2015, p13) said of the objects she took to school, “I was pleased to be able to show them off and with the social success they promised, I began bringing toys and books to school”.

4.6.2 Recommendations to other persons with autism

Some sources also recommended that other persons with autism should work on improving their PNT social skills and personal qualities and provided advice as to how to do so (Harvey, 2008; Jarvis, 2008; Arman, YouTube, 2012a; Nathan, YouTube, 2014b). Sillygayboy (YouTube, YouTube, 2011b) said, “Don’t be so shy because if you are shy then you are kind of leaving it for people to make friends with you and if you aren’t shy you have more of a pick of different people”. Sources also recommended participating in social skills training (Harvey, 2008; Jarvis, 2008; Simone, 2010; Richard, Healthtalk, 2014e). Simone (2010, p104) wrote, “Young people with AS have told me that

social skills training has really helped them. Explore the options in your area, through your local autism services, school, and therapists. There are also books on body language, etc”.

Various sources provided rules and tips as to how to socialise, make friends, and maintain friendships (Victoria, YouTube, 2013; Sillygayboy, 2011b; Moss, 2014; Nathan, YouTube, 2014b). Nathan (YouTube, 2014b) recommended, “Tip number one quality over quantity”, “second tip. Don’t be so desperate for friends that you settle for someone who takes advantage of you” and “tip number three. Find your group”. Andrew (YouTube, 2011a) said, “So the answer to this is what I call pockets. You have to find some pocket in the city some smaller areas that you can be more familiar”. Examples of pockets were cited as work or jogging. Other sources also recommended joining special interest groups (Harvey, 2008; Andrew, YouTube, 2011a; Moss, 2014; Alex, YouTube, 2014a). Moss (2014, p69) said, “If you are studying and want to be social, I recommend joining study groups”.

A number of sources described the anticipated future successes of other persons with autism that they thought they would have if they used their recommended strategies (Simone, 2010; Moss, 2014; Alex, YouTube, 2014a; Nathan, YouTube, 2014b). Jarvis (2008, p31) said, “My vision for the future in helping AS people develop social skills is to allow them to practise these skills in a safe, supportive environment”. Simone (2010, p10) stated, “I am relieved to know that each day, more and more Aspie women are joining web forums, small group discussions, and friendship circles, to share advice on how to navigate the neurotypical world map”.

4.6.3 Failure in socialising and friendship

Many sources described their past experiences of when they had failed to socialise, make a friend or didn’t have any friends (Debumaiya, YouTube, 2010; Nathan, YouTube, 2014b; Sam, Healthtalk, 2014c; Catherine, Healthtalk, 2014d). Richard (Healthtalk, 2014a) said, “But I didn’t have friends and at the time I think my understanding of that was, I don’t have an interest in football,

that loses me most of my friends". Several sources recounted that as children they had tried to make friends but had failed to do so (Pears, 2004; Ian, Healthtalk, 2010c; Richard, Healthtalk, 2014a; Sam, Healthtalk, 2014c). Jarvis (2008, p28) said, "I had few friends as a child and I was poor at maintaining these friendships into adulthood".

Sources described more instances of failing to socialise, make friends and maintain friendship⁶⁰ (Harvey, 2008; Richard, Healthtalk, 2014a; Nathan, YouTube, 2014b; Sam, Healthtalk, 2014c). Andrew (YouTube, 2011a) described his experience of trying to make friends and said, "All of the things I tried were very challenging and they didn't often work". Brown (2008 p64) stated of her experiences at school, "No one was unkind to me, I just didn't have a friend". Pears (2004, p12) similarly said, "I had no friends to meet, no places to go".

Some sources described that they thought it was hard for them to socialise, make friends, and maintain friendships (Alex, Healthtalk, 2010e; Sillygayboy, YouTube, 2011b; Alex, YouTube, 2014a; Harris, 2015). Nathan (YouTube, 2014b) said, "So this week I'm going to be addressing one of the most difficult things about growing up as an Aspie. Making friends" and Kerry (YouTube, 2014c) commented, "Friendship is something that's important to us probably because its difficult for us to make friends". Andrew (YouTube, 2011a) talked about how he couldn't understand that despite trying hard to, why other people were able to make more friends than he did.

Some sources also anticipated failure in the future when trying to socialise, make friends, and maintain friendships for themselves (EvieMay, YouTube, 2011c; Arman, YouTube, 2012a; Victoria, YouTube, 2013; Kerry, YouTube, 2014c). Kerry (YouTube, 2014c) said,

With me moving to another province its gonna be difficult because I'm gonna have to go out of my way to actually make new friends and

⁶⁰ A ratio of two to one for the codes of negative experience to positive experience was recorded in the data analysis.

that isn't going to be an easy thing for somebody like me with Aspergers Syndrome so it's gonna be a challenge.

Various sources provided reasons why they had failed to socialise, make friends, or maintain a friendship. Not sharing the same interests as the PNT was one reason (Lawson, 2001; Jarvis, 2008; Mary, Healthtalk, 2010b; Richard, Healthtalk, 2014a). Richard (Healthtalk, 2014a) said:

I was different from most of my age group in that I was a lot more interested in maths and physics and not at all interested in football and that made me different. I would rather sit and read than go and play a sport. That made me different. So if I didn't have any friends, it might have just been because of that.

Several sources attributed their failure to socialise, make friends, and maintain friendships to having a lack of PNT personal qualities (Stephen, YouTube, 2010m; Sillygayboy, YouTube, 2011b; Arman, YouTube, 2012a; Catherine, Healthtalk, 2014d). Simon (Healthtalk, 2010k) stated that the strange social system of persons with autism made it difficult for them to make friends. Pears (2004, p175) described how being with other people for extended periods of time felt like confrontation and said, "People were difficult to please; yet sometimes, too accepting. Sometimes, they compelled me; yet sometimes, they repelled me. There was never a balance. Friends could easily become enemies, and vice versa".

Different sources were critical of their social skills that they thought were lacking compared to the PNT (Lawson, 2001; Oliver and Susie, 2010f; Erinclem, 2012c; Victoria, YouTube, 2013). EvieMay (YouTube, 2011) stated that she couldn't just walk up to someone and say "Hello". Jarvis (2008) and Lawson (2001) described that in conversation they talked too much about a favourite subject and couldn't read PNT body language. Simone (2010, p28) said of entering adolescence, "All at once, my idiosyncrasies became very uncool, almost overnight. My social deficits, which prior to that point had just been differences, became glaring holes in my persona". Harvey (2008, p42) wrote, "People would simply walk away as they couldn't understand my body language, and perhaps

thought me a bit rude or ignorant". McCabe (2003, p140) stated, "This broad base of interest or knowledge helps me get past my lacking social skills at times".

Two sources, James (Healthtalk, 2010a; Alex, YouTube, 2014a), thought the PNT shared the view that persons with autism found it more difficult to make friends. When describing his experience of winning Prom King James (Healthtalk, 2010a) said, "It just sort of shows you how much people can sort of think you would never make any friends and you would never really be that popular".

Some sources viewed it as their responsibility to adapt to the PNT and thereby increase their success at socialising, making friends, and maintaining friendships (Jarvis, 2008; Ian, Healthtalk, 2010c; Victoria, YouTube, 2013; Sam, Healthtalk, 2014c). A number of sources advocated achieving a degree of mastery over their social skills to enable them to be more successful at socialising, making friends, and maintaining friendships. Nathan (YouTube, 2014b) said, "Develop that special interest and become a master at it and I promise you that people will appreciate your talent" and Arman (YouTube, 2012a) stated he wanted to "become the best person I can be". Ian (Healthtalk, 2010c) described how he tried his best when socialising with the PNT. Harris said (2015, p201):

Because of their knowledge of their weak points in social interaction, people on the spectrum can consciously work at developing their ability to relate and can reach a level of quality social interaction equal to, if not surpassing that of their neurotypical peers.

Two sources, however, acknowledged that the failure to socialise, make friends, and maintain friendships may be influenced by the other person. Victoria (YouTube, 2013) recognised that at times you can try too hard to be friends with someone who just doesn't want to be a friend. Nathan (YouTube, 2014b) shared this view and says, "No matter what you do not everyone is going to like you".

Occasionally sources challenged the PNT meaning of sociality and friendship (e.g., Harris, 2015). Simone (2010, p95) said that she and other girls with autism wanted to be accepted for who they were and Brown (2008) that she didn't feel the need to socialise anymore. Similarly, Pottage said (2008, p39):

My strategies now are to be very public about my Asperger Syndrome and not to feel the need to apologise if my behaviour is odd to neurotypical people, not to feel guilt and shame whenever I wish to be alone because a social situation is too much for me to handle.

One source also stated it was alright not to be bothered about not having friends (e.g., Richard, Healthtalk, 2014a) and another not to like or to be liked by everyone (e.g., Nathan, YouTube 2014b).

4.6.4 Sharing of experiences with other persons with autism

Some sources described that they thought it was hard for other persons with autism to socialise, make friends, and maintain friendships (Alex, Healthtalk, 2010e; Sillygayboy, YouTube, 2011b; Alex, YouTube, 2014a; Harris, 2015). Simone (2010) thought that whether girls with AS wanted them or not, most had few or no friends. Jarvis (2008) thought that some persons with autism may find it difficult to develop social relationships. Victoria (YouTube, 2013) said, "Aspies find it hard to figure out who their real friends are". Debumaiya (YouTube, 2010) stated, "A lot of us lying in the autism spectrum have a great deal of difficulties with friendships making friends".

Some sources also anticipated failure in the future for other persons with autism when they tried to socialise, make friends, and maintain friendships for (Harvey, 2008; Pottage, 2008; Victoria, YouTube, 2013; Alex, YouTube, 2014a). Victoria, (YouTube, 2013) said, "If you're having trouble finding friends and if you don't know where to really start here's something you can try doing".

A number of sources also felt that other persons with autism shared their lack of PNT social skills and personal qualities and this accounted for their failures in

socialising and friendship (Arman, YouTube, 2012a; Victoria, YouTube, 2013; Alex YouTube, 2014a; Nathan, YouTube, 2014b). Simone (2010) described the flight-or-fight reaction that she felt all persons with AS had to social contact. Harris (2015) described the social confusion experienced by girls and women with autism. Sillygayboy (YouTube, 2011b) described how he thought persons with autism were shy and that this prevented them from making friends. Richard (Healthtalk, 2014e) said, "Aspies don't have empathy". Simone (2010, p209) stated of herself and other girls with Asperger Syndrome, "If we never received social skills training and have had many poor relationships with people – friendships that soured, etc - we may get worse at socialising rather than better, and more reclusive than ever".

Chapter Four has presented the themes I identified from my data analysis with respect to my understanding of the meaning described by the sources of sociality and friendship. These themes will form the basis on which claims will be made later in my thesis, and enable me to make a contribution to knowledge by answering my research questions:

1. What meaning do persons with autism describe of the phenomena of sociality and friendship?
2. What barriers do persons with autism encounter in experiencing sociality and friendship?
3. How do persons with autism see these barriers being overcome?

Having described the themes I had identified from my thematic analysis, I now begin Chapter Five by discussing the implications for my understanding of the meaning of sociality and friendship from the perspective of the sources.

5 Chapter Five: Discussion and implications for professional practice

5.1 Introduction

As I have previously stated in my thesis, for me, the medical model of disability understanding of autism has given rise to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). In defining my theoretical position, my aim is for the outcome of my research to contribute to resolving this conundrum. To do so, my theoretical position, reflected in my discussion, presents possibilities for an enabling narrative of sociality and friendship for persons with autism that: 1) deconstructs the binary of autistic and PNT sociality, and, therefore, advances a challenge to this dominant discourse on sociality and friendship; and 2) argues for a range of sociality and friendship possibilities across being human.

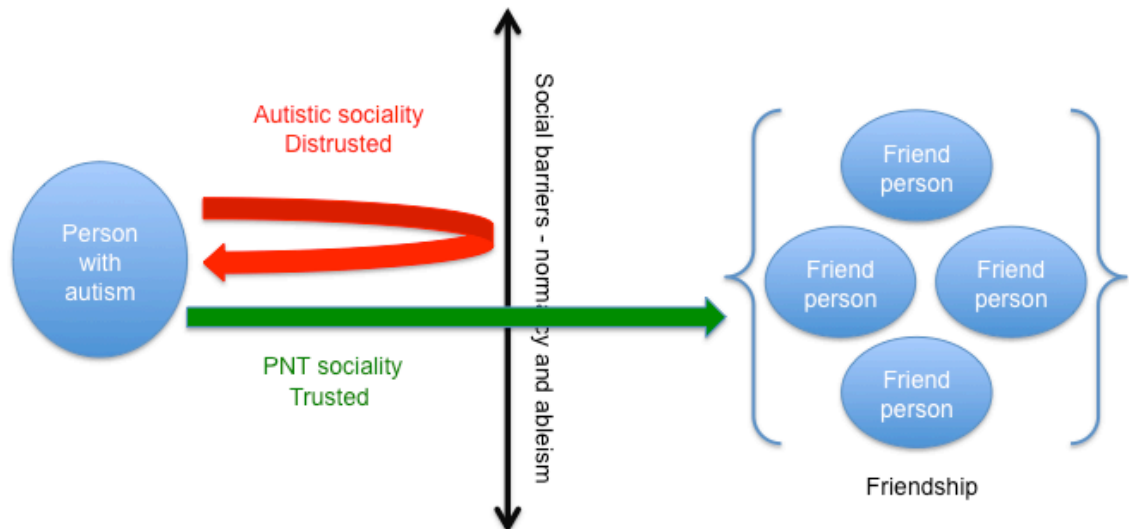
However, this chapter isn't just about describing the meaning of these phenomena of my sources from their perspective. It's also about challenging my researcher positionality and acknowledging the limitations and academic discourse as to how I had conducted my research. Chapter Five, therefore, also presents areas for further research that I claim have emerged from the themes I have identified. I also consider how the meaning of sociality and friendship for persons with autism from their perspective could inform my own and other professional practice.

Any claims about knowledge I make that provide answers to my research questions, I argue to be trustworthy (Lincoln and Guba, 1985) within the confines of my thesis. It isn't my intention to generalise about the meaning of sociality and friendship for all persons with autism. I, therefore, position my claims about knowledge by referring to the meaning of sociality and friendship for the sources or persons with autism in my study. I begin my discussion by presenting my understanding of the meaning of sociality and friendship from the

perspective of the sources.

5.2 My understanding of the meaning of sociality and friendship

Figure Four



Sociality pathways and social barriers to making friends and maintaining friendships for persons with autism

My analysis of the data evidenced that the sources described from their perspective a distinct meaning of sociality to that of the PNT that resulted in two sociality pathways as shown in Figure Four, i.e., the binary of autistic and PNT sociality. To describe this meaning, I chose the terms 'trusted' and 'distrusted'. A widely held definition of trust was presented in the literature as “a psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behaviour of another” (Rousseau et. al.,⁶¹ 1998, p395). In the context of my research, trusted represented the positive outcome that the sources expected of PNT sociality in making friends and maintaining friendships. Distrusted was chosen to mean the opposite of trusted, that I defined as the negative outcome that the sources expected of their sociality in making friends and maintaining friendships, that I have labelled

⁶¹ These authors presented a multidisciplinary view of trust and was cited by many and more recent authors, e.g., Haselhuhn et. al., (2015) and Levine and Schweitzer (2015).

as autistic sociality in Figure Four. The binary of autistic and PNT sociality I argue has resulted in the conundrum that despite the sociality of persons with autism, the positive experience of friendship that they desire and enjoy is often difficult for them to achieve.

As shown in Figure Four, my understanding of the meaning of sociality and friendship described by the sources was that PNT sociality was the trusted and only pathway to making friends and maintaining friendships. Their perspective of themselves as having a distinct autistic sociality I argue didn't result from a lack of social skills but from the disabling social barriers of normalcy and ableism. These social barriers, for me, prevented the sources from making friends and maintaining friendships. For the sources, the social barriers of normalcy and ableism also positioned their sociality as inferior, other, and labelled as distrusted. Furthermore, the PNT meaning of sociality that they regarded as being distinct from their autistic sociality had been internalised by the sources as the correct, obtainable, and only way of being.

My discussion is structured around the different understandings of autism that I explored in Chapter Two that have shaped my theoretical position and my interpretation of the key concepts of relevance to my focus of enquiry. In my discussion that follows, I critically evaluate my themes in light of the findings of the literature review. My aim of the discussion is to achieve the aim of the outcome of my research, i.e., to contribute to resolving the conundrum that despite their sociality the positive experience of friendship that persons with autism desire and enjoy is difficult for them to achieve. In doing so, I present possibilities for an enabling narrative of sociality and friendship for persons with autism that: 1) deconstructs the binary of autistic and PNT sociality, and, therefore, advances a challenge to this dominant discourse on sociality and friendship and; 2) argues for a range of sociality and friendship possibilities across being human. In my discussion, I cite as examples sources that support the arguments I present.

I begin by questioning, challenging, and disrupting the medical model of disability ideology that I have rejected in terms of my theoretical position as I

argue it doesn't present possibilities for an enabling narrative of sociality and friendship for persons with autism.

5.3 Medical model of disability ideology

As I explored in Chapter Two, the dominant understanding of autism lies with the medical model of disability. Today, autism is diagnosed using the medical model of disability criteria (WHO, 2010; APA, 2013b) and as a result of social and cultural practice, autism is often understood as a medical problem (O'Dell, et. al., 2016). In Chapter Two, I rejected the medical model of disability ideology, as it doesn't present possibilities for an enabling narrative of sociality and friendship for persons with autism.

My analysis of the data evidenced that for the sources, the medical model of disability ideology, labelled their sociality from their perspective as a separate and distrusted pathway to making friends and maintaining friendships that I labelled autistic sociality in Figure Four (e.g., Richard, Healthtalk, 2014e). The autistic sociality pathway encountered disabling social barriers that didn't allow friends to be made or friendships to be maintained (e.g., Mary, Healthtalk, 2010l). Making friends and maintaining friendships was perceived by the sources as being contingent on describing the same meaning of sociality as the PNT (e.g., Simon, Healthtalk, 2010k), depicted by the trusted pathway in Figure Four.

The themes I identified from my data analysis I argue, described in sections 4.2 to 4.6, demonstrated that to the contrary, the sources described meaning from socialising, making friends, and maintaining friendships (e.g., Richard, Healthtalk, 2014b). These findings I claim also challenged the view that social interaction and communication was abnormal or deficient in the persons with autism in my study (e.g., Ian, Healthtalk, 2010c), and, therefore, the positioning of autism in diagnostic criteria embedded in the medical model of disability ideology.

For me, positioning autism in a clinical or mental health category that is

exclusively aligned with the medical model of disability gives autism its official status in society as a disease, a mental disorder, or a health problem (Molloy and Vasil, 2002). Kapp et. al., (2013) reviewed previous research and found that parents, professionals, and the general public generally positioned autism within the medical model of disability. As argued by Molloy and Vasil (2002), this official standing implied that a consensus had been reached by our society that autism is a medical condition that needs to be preferably cured, or at the very least to be treated to ameliorate the symptoms. From my perspective, the symptoms of abnormal or deficient sociality in persons with autism were positioned in the literature as needing to be treated and cured, to align with the wellness represented by PNT sociality (Wing, 1996; WHO, 2010; APA, 2013b).

To the contrary, from the perspective of many academics, and as I have outlined in relation to my own perspective, the autism neurotype isn't a mental disorder or a disease that can be caught. Chown (2017, p70) stated, "We have to live with autism being included in international classifications of diseases and mental disorders, but that does not mean that it is either". For me, autism has nothing to do with illness and the PNT state cannot be equated with wellness. As proposed by O'Dell et. al., (2016) the PNT production of 'ability' in contrast to autism that was produced as 'disability' is a dominant understanding that needs to be challenged that I support.

Other authors have challenged this dominant understanding. For example, Shyman (2015) stated that in some cultures there were no labels for autism and a reluctance to pathologise it as an illness. Allred (2009) argued AS wasn't a mental disorder or a psychiatric condition as it failed to meet the requirements of the APA's criteria (APA, 2013b). These authors also claimed that persons with autism had different ways of socialising that required equal respect by society as was demonstrated by the persons with autism in my study (e.g., Lawson, 2001). As I examined in Chapter Two, this dominant understanding of autism as a medical problem (O'Dell et. al., 2016) has arisen as a result of social and cultural practice that I now discuss in the context of my theoretical position.

5.3.1 The social construction of autism

From my perspective, the sources only regarded their meaning of sociality and friendship (e.g., Pears, 2004) as outside the realms of normality due to the influence of cultural and social practice. My findings, therefore, support the social construction theory of autism (Molloy and Vassil, 2002), i.e., for the persons with autism in my study, their meaning of sociality and friendship that positioned from the PNT perspective as impaired has, for me, been socially constructed by society as a disorder and labelling as a disability.

Special education has played a pivotal role in the social construction of autism (Molloy and Vassil, 2002). In the quest of professionals to employ conventional teaching methods, children with autism have been subject to interventions to ameliorate their perceived symptoms or preferably cure their non-PNT behaviours (Carter et. al., 2004; Chamberlain, Kasari, and Rotheram-Fuller, 2007). Social skills training as an intervention has been researched by these authors to address perceived abnormalities or deficits in socialisation and friendship of children with autism. Dominant medical model of disability understandings of friendship, I argue, have established the norms for the social skills needed to make friends and maintain friendships (Bertilsdotter Rosqvist, Brownlow, and O'Dell, 2015).

My analysis of the data evidenced that the sources had adopted the PNT meaning of sociality and friendship (e.g., Oliver and Susie, Healthtalk, 2010f). Whilst sources had friends and had maintained friendships (e.g., Ben, YouTube, 2012b) their sociality was regarded by them as inferior, lesser, and other, and distinct from PNT sociality (e.g., Erinclem, YouTube, 2012c). McGuire and Michalko (2011) supported the view that autism was a social construction or a puzzle of the mind that needed to be solved. To the contrary, they viewed persons with autism as examples of “the fundamental human features of uncertainty, of the incompleteness and partiality of communication”, and “as a reminder that we live in the risk of incompleteness” (McGuire and Michalko, 2011, p164). Broderick, Reid, and Weatherley-Vale (2008, p138) stated:

Research and practice have effectively defined individual lives under the pathology heading without addressing the politics of knowledge, without allowing for significant personal meanings of those categorised persons (the persons we serve) to be valued as knowledge.

Therefore, I claim that as posited by these authors, the significant personal meaning of sociality and friendship of the sources (e.g., Brown, 2008) hadn't been valued by a PNT-dominated society as knowledge.

Biklen, (2005, p65) argued, "Autism is not a given condition or set of realities – at least, it is not "given" or "real", *on its own*. Rather, autism is and will be, in part, what any of us make it" (authors italics). Shyman (2015) claimed that the concept of autism is constantly developing based on current understandings and on the changing roles of persons with autism in society. These changing roles included the movement of persons with autism to positions of power in society that can most readily influence how autism is conceptualised. The reality is that these positions in, for example, politics, psychiatry, and education are for now mainly held by the PNT (Molloy and Vasil, 2002). The symbiotic relationship between knowledge and power (Weiler, 2011) has resulted in "The voices of those who have been labelled are rarely incorporated into this accepted body of knowledge" (Molloy, and Vasil, 2002, p667). The opinions of persons with disabilities on disabilities aren't generally regarded with the same validity as the views of medical experts (Brisenden, 1986). For me, the perspective of persons with autism, as described by the sources (e.g., Ben, YouTube, 2012b) hasn't been adequately represented in the current social construction of autism presented in the literature (Molloy and Vasil, 2002).

My analysis of the data supported the position of Biklen (2005, p65) who argued, "the importance of *interpreting the mind and body from an insider perspective*" (authors italics). At present, the voices of persons with autism, including those of the sources (e.g., Richard Healthtalk, 2014b), are largely absent from the conceptualisation of sociality and friendship. From my perspective, the result has been the construction of social barriers and the labelling of the sociality of the sources as a separate and distrusted pathway by

them (e.g., Victoria, YouTube, 2013) to making friends and maintaining friendships, as depicted in Figure Four. As I examined in Chapter Two, the medical model of disability understanding of autism has also been adopted by academics in the research community that I now discuss in the context of my theoretical position.

5.3.2 Researching disability

As I presented in Chapter Two, the focus of academics on researching disability has been from the perspective of the PNT as the ideal state⁶² (Mallet and Runswick-Cole, 2014). This approach to researching the sociality and friendship of persons with autism assumes lesser social engagement and fewer friends with friendships of poorer quality than the PNT (Conn, 2016). In contrast, disability studies challenge the status quo that persons with autism are lesser beings and experience phenomena such as sociality and friendship in an inferior context to the PNT (Mallet and Runswick-Cole, 2014).

My analysis of the data evidenced that the meaning the sources described of sociality and friendship generally supported the academic view of the PNT perspective as the ideal state (Conn, 2016) (e.g., Victoria, YouTube, 2013). For many of the sources, their meaning of sociality and friendship was that they experienced fewer social engagements (e.g., Harvey, 2008), had fewer friends (e.g., Debumaiya, YouTube, 2010), and poorer quality friendships than the PNT (e.g., Ian, Healthtalk, 2010c).

From my perspective, the label of autism had cast the sources sociality, friends, and friendships in the category of 'inferior other' (e.g., Jarvis, 2008). Furthermore, this positioning of their sociality and friendship experiences as bodies in need of repair and the dis/human (Goodley and Runswick-Cole, 2016) was regardless of the number of opportunities to socialise or friends the sources had, or the friendships they had made (e.g., McCabe, 2003). The friendships of the sources (e.g., Arman, YouTube, 2012a), was, I argue, only

⁶² I'm not implying that researching from the PNT as the ideal state may or may not have been a conscious decision by the researcher. Merely, that this is the perspective adopted in the published literature.

regarded as being of poorer quality if measured against the PNT perspective of friendship (e.g., James, Healthtalk, 2010a). I claim that the sources, like the PNT person, considered their relationships to be of a high quality (e.g., Erinclm, YouTube, 2012c). Other authors (Bertilsson Rosqvist, Brownlow, and O'Dell, 2015) have reached a similar conclusion.

Harper (1991, p541) stated, research perpetuates the “two group mentality (normal-disabled)” and presents unchallenged cultural narratives of impairment based on power and privilege (Paxton-Burrsma and Mariage, 2011). These cultural narratives, that I also posit need to be challenged, positioned the sources sociality as lesser and other (e.g., Richard, Healthtalk, 2014e) that encountered the disabling social barriers of normalcy and ableism as shown in Figure Four.

The meaning sources described of sociality and friendship (e.g., Simon, Healthtalk, 2010k) I argue didn't generally support the premise of disability studies (Mallet and Runswick-Cole, 2014). From my perspective, many of the persons with autism in my study thought it was their responsibility to describe the same meaning of sociality and friendship as the PNT (e.g., James, Healthtalk, 2010a). The meaning described by the sources (e.g., Jarvis, 2008), for me, didn't generally challenge the status quo, i.e., that persons with autism were lesser beings than the PNT and were describing an inferior meaning of sociality and friendship (e.g., Pottage, 2008).

The meaning of sociality and friendship described by the sources (e.g., Simon, Healthtalk, 2010i) I claim didn't contribute to dispelling the myth in the literature that persons with autism are lesser beings, experience phenomena, and describe meaning in an inferior context in comparison to the PNT (Conn, 2016). This adoption of the PNT perspective of sociality and friendship, for me, positioned the sociality of the sources (e.g., Harris, 2015) as a separate and distrusted pathway to making friends and maintaining friendships as depicted in Figure Four.

To the contrary, I argue that my analysis of the data evidenced the sociality of the sources isn't a distinct pathway to making friends and maintaining friendships but represents a range of possibilities across being human. What is required is broader constructions of sociality that deconstructs the binary of autistic and PNT sociality and, therefore, advances a challenge to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). What is needed, I argue, is a different enabling understanding of autism as posited by my theoretical position. I now critically evaluate my themes in the context of my understanding of autism, and I begin with the social model of disability ideology.

5.4 Enabling narratives of autism

5.4.1 The social model of disability ideology

In Chapter Two, I explored the social model of disability understanding of autism (Oliver, 1983) that acknowledges the frequently disadvantaged outcome of persons with autism in a PNT dominated society (Beardon, 2017). I concluded that this ideology aligned with my theoretical position by presenting possibilities for an enabling narrative of sociality and friendship of persons with autism. However, my analysis of the data evidenced that the meaning described of sociality and friendship by the sources in my study didn't support the social model of disability understanding of autism (e.g., Victoria, YouTube, 2013).

For me, today's society desires ontological security or confidence in the nature of the social world, and this concept is challenged by disability (Campbell, 2009). From my perspective, the desire of many of the sources to achieve greatness in terms of social skills and personal qualities (e.g., Simone, 2010) was related to their security of the nature of being in society and their belief in the dominant medical model of disability ideology, i.e., the sources (e.g., James, Healthtalk, 2010a), wished the PNT to feel secure in the meaning they described of sociality and friendship, as they believed this presented them with

the greatest chance of success in socialising, making friends, and maintaining friendships.

I claim there was a general absence of a challenge by the sources (e.g., Victoria, YouTube, 2013) to the PNT status quo as to how to socialise, make friends, and maintain friendships, and I argue this may have reflected their own experiences of failure. Various sources described many past experiences of trying but failing to socialise, make friends, and maintain friendships (e.g., Pears, 2004). Having failed to socialise, make a friend, or maintain a friendship resulted in these sources being excluded from PNT social and friendship groups (e.g., Brown, 2008). I argue it may have been that the sources regarded maintaining this PNT medical model of disability ideological perspective as being in their own best interest. Adhering to the PNT meaning made persons with autism feel secure in terms of knowing what they thought they had to achieve to optimise their chances of success in socialising, making friends, and maintaining friendships (e.g., Simone, 2010). For me, this ontological security of PNT sociality and friendship, labelled the sociality of the sources (e.g., Simon, Healthtalk, 2010k) as a distrusted pathway to making friends and maintaining friendships, encountering the disabling social barriers shown in Figure Four.

From the perspective of many academics, and as I have outlined in relation to my own perspective, the discourse of neurodiversity (Jaarsma and Welin, 2011) has challenged the medicalisation of autism, i.e., this discourse positions autism as “both a possible strength and a nuanced difference rather than a one-sided shortcoming or deficit” (Brownlow, Bertisdotter Rosqvist, and O’Dell, 2015, p188). The discourse of neurodiversity that forms part of my theoretical position, posits autism as being “within a framework of neurological diversity, as one of many variations in the functionality of the human brain”, and “including alternative social functionalities” (O’Dell et. al., 2016, p172). Other authors have also challenged the position of autism as a deficit based, medical model of disability conceptualisation and argued that autism should be re-framed as a human difference (Molloy and Vasil, 2002; Allred, 2009; Jaarsma and Welin, 2011; Kapp et. al., 2013). Autism is a “valid biological category of atypical brain

wiring that needs to be respected” (Verhoeff, 2015, p445). Jaarsma and Welin (2011) also claimed that autism conferred rights to persons with autism and called for this label to be valued, recognised, and accepted by society. However, for me, the meaning described of sociality and friendship by the sources didn’t support the neurodiversity discourse (e.g., Arman, YouTube, 2012a).

I also claim that the sources had experienced a disadvantaged outcome in socialising, making friends, and maintaining friendships as a result of the PNT dominated society that they inhabit (e.g., Debumaiya, YouTube, 2010). Andrew (YouTube, 2011a) said of his life at college, “If I was lucky I would have maybe two three friends by the end of the semester” and Jarvis (2008), “I had few friends as a child”. Brisden (1986, p173), wrote, “The medical model of disability is one rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual”. This statement, I claim is true for the meaning described of sociality and friendship by the sources (e.g., Catherine, Healthtalk, 2014d) and is indicative of the disadvantaged outcome they experienced in socialising, making friends, and maintaining friendship in comparison to the PNT.

From my perspective, what is required, in support of the social model of disability, is the wider acceptance by the PNT that autism is one variant of human neurology (O’Dell, et. al., 2016). Autism and, therefore, the meaning of sociality, for me, shouldn’t be rooted in the medical model of disability ideology or included in DSM-5 (APA, 2013b) or ICD-10 (WHO, 2010). I argue that whilst autism remains classified as an illness, the sources (e.g., Pottage, 2008) will continue to view their sociality as a separate and distrusted pathway to making friends and maintaining friendships that will encounter the disabling social barriers of normalcy and ableism shown in Figure Four. Furthermore, the medical model of disability ideology will perpetuate the disadvantage outcome of persons with autism in our society in terms of socialising, making friends, and maintaining friendships (e.g., Richard, Healthtalk, 2014a).

As I explored in Chapter Two, CAS thinking also aligns with my aim for the outcome of my research to contribute to resolving the conundrum of persons with autism socialising but finding it difficult to make friends and maintain friendships. I now critically evaluate the significance of the findings of my research in the context of CAS.

5.4.2 Critical autism studies (CAS)

As I explored in my literature review, CAS (Davidson and Orsini, 2010) compliments critical disability studies (Vehmas and Watson, 2014) but has a focus on researching autism. I concluded in Chapter Two that CAS supports my theoretical position by questioning the dominant medical model of disability understanding of autism and rejecting society's references to the PNT norm (O'Dell, et. al, 2016).

I claim the meaning described by the sources of sociality and friendship wasn't generally supportive of the objective of CDS (e.g., Victoria, YouTube, 2013), i.e., the majority of persons with autism in my study didn't contribute to deconstructing the established narrative of a lack of social skills and difficulties in making friends and maintaining friendships of persons with autism (e.g., Stephen, Healthtalk, 2010m). For me, the meaning the sources described of sociality and friendship was positioned in the established medical model of disability ideology (e.g., Mary, Healthtalk, 2010l), and reinforced the impaired versus non-impaired dualism (Vehmas and Watson, 2014). As argued by these authors, dualism has resulted in the dominance of those seemingly faring well (the PNT) and has labelled the meaning of sociality and friendship of those faring less well (persons with autism), as having lesser value (e.g., Jarvis, 2008). Similarly, my analysis of the data evidenced that the sources positioned the PNT meaning of sociality and friendship as the 'norm' (e.g., Simone, 2010) that wasn't supportive of CAS thinking.

In my literature review, I interpreted through the lens of my theoretical position a number of key concepts of relevance to my focus of enquiry. I now critically evaluate my themes in the light of these concepts. I begin with ToM.

5.5 Theory of Mind

As I presented in Chapter Two, my theoretical position supports the cross-neurological ToM concept (Beardon, 2008b; 2017) and double empathy hypothesis (Milton, 2014). In supporting my understanding of autism, both theories present possibilities for an enabling narrative of sociality and friendship for persons with autism.

My analysis of the data evidenced that the persons with autism in my study were able to impute meaning from their sociality and friendship experiences (e.g., Catherine, Healthtalk, 2014d). The sources understood their desire to socialise, make friends, and maintain friendships (e.g., Mary, Healthtalk, 2010l). Many of the persons with autism in my study understood their own emotions and imputed the ones they enjoyed (e.g., Erinclem, YouTube, 2012c) and those that had upset them (e.g., Pears, 2004). These meanings were frequently translated by the sources into their successes and failures in socialising, making friends, and maintaining friendships (e.g., Alex, YouTube, 2014a). Some sources were also able to mentalise the actions they believed they needed to instigate to achieve positive sociality and friendship experiences in the future (e.g., Victoria, YouTube, 2013). Several of the persons with autism in my study also hypothesised as to how their future experiences of socialising and friendship would make them feel (e.g., Kerry, YouTube, 2014c).

I posit these sources weren't just imputing their own mental states, but some claimed to know the meaning of sociality and friendship of other persons with autism (e.g., Simone, 2010). Meanings included that other persons with autism desired to socialise, make friends, and maintain friendships (e.g., Nathan, YouTube, 2014b) and the emotional difficulties they experienced in doing so (e.g., Sillygayboy, YouTube, 2011b). Some sources devised and recommended strategies for other persons with autism to use to increase their chances of success in socialising, making friends, and maintaining friendships (e.g., Moss, 2014) and provided support and encouragement in doing so (e.g., Alex, YouTube, 2014a). From my perspective, many sources were reflective and critical thinkers with respect to the meaning they described (e.g., Jarvis, 2008).

Some sources also critically reflected on the meaning that they claimed to know was described by other persons with autism of these phenomena (e.g., Debumaiya, YouTube, 2010).

For me, this ability of these sources to think critically about their sociality and friendship experiences and those of others with autism was evidence of a ToM, i.e., persons with autism could impute mental states in themselves and others (e.g., Harris, 2015). I claim that their ToM wasn't deficient or impaired. As argued by Milton (2014), a deficit in ToM in persons with autism isn't factual but should more accurately be described as a "working model" (p796). I support this position and argue that their ToM enabled the sources to impute meaning from their sociality and friendship experiences for themselves (e.g., Harvey, 2008) and for some sources of other persons with autism (e.g., Kerry, YouTube, 2014c).

I also support the position of Chown (2012 and 2017) that whilst persons with autism were expected to understand PNT sociality and develop a PNT ToM, the PNT weren't expected by them to acquire an understanding of the sociality of persons with autism or to or develop their ToM (e.g., James, Healthtalk, 2010a). Milton (2012) concluded that (2012, p886):

One could say that many autistic people have indeed gained a greater level of insight into non-AS society, and more than *vice versa*, perhaps due to the need to survive and potentially thrive in a non-AS culture. Conversely the non-AS person has no pertinent personal requirement to understand the mind of the 'autistic person' unless closely related socially in some way.

Beardon (2008b) shared this perspective of Milton (2012; 2014) on the power imbalance between the PNT and persons with autism. This author argued that the emphasis was on the person with autism to change their sociality to be more like that of the PNT. There was no corresponding requirement of the PNT to do the same. Beardon (2008b) regarded this insistence on persons with autism to change their sociality as a PNT demand for them to give up their sense of self and way of being. I argue that the sources (e.g., Jarvis, 2008),

regarded it as their exclusive responsibility to overcome the disabling social barriers of normalcy and ableism by developing a PNT ToM and sociality.

I claim that from the perspective of the sources, their non-PNT ToM resulted in a sociality that they distrusted and caused them to encounter disabling social barriers that didn't allow friends to be made and friendships to be maintained (e.g., EvieMay, YouTube, 2011c). For me, making friends and maintaining friendships was for the sources contingent on having a PNT ToM, that enabled them to impute this meaning of sociality (e.g., Oliver and Susie, Healthtalk, 2010f), depicted by the trusted pathway in Figure Four. To the contrary, from the perspective of many academics, and as I have outlined in relation to my own perspective, I posit the sources had a ToM that argued for a range of sociality possibilities across being human. I now examine this concept of sociality in the context of the findings of my research.

5.6 Sociality

My review of the literature concluded that humans are sociable by nature and the most striking characteristic of the human is its unique sociality (Paige-Fiske, 1992; Haslam et. al., 2009). I also concluded in Chapter Two that the meaning of sociality described by persons with autism aligns with my theoretical position, i.e., shared behaviours that are common to both neurotypes that overlap, with some being more likely to be observed in persons with autism than the PNT. In addition, each person with autism is a unique individual whose meaning of sociality is exclusive to them.

My analysis of the data evidenced that the sources wanted to socialise (e.g., Sam, Healthtalk, 2014f) and had, as conceptualised by Maslow's Hierarchy of Needs (Maslow, 1943), an intrinsic need to be social (e.g., Pottage, 2008). Sources understood their own need to socialise (e.g., Harvey, 2008). Some persons with autism in my study were able to attribute this need not only to themselves but also to other persons with autism (e.g., Lawson, 2001). Many of the persons with autism in my study had a need to feel loved and to belong (e.g., Erinclm, YouTube, 2012c). In the context of social exchange theory

(Emerson, 1976), a number of sources felt they had a choice in the persons they socialised with (e.g., Nathan, YouTube, 2014b). This choice was in terms of qualities in people that would make socialising for them a positive experience (e.g., Harris, 2015). Several sources also entered into some form of emotional support and social interaction with the persons they socialised with (e.g., Moss, 2014). In the context of self (Sedikides, Gaertner and O'Mara, 2011), the meaning the sources described of sociality was unique to them as described in the theory of individual self (e.g., Victoria, YouTube, 2013). Relational self was also expressed as a meaning by some sources, i.e., the process of sociality was thought to be, by several sources, with individuals who had similar characteristics to themselves (e.g., Ian, Healthtalk, 2010c). Various sources also described the meaning of collective self by engaging with communities in the form of shared personal interests (e.g., Richard, Healthtalk, 2014b).

From the perspective of many academics, and as I have outlined in relation to my own perspective, it is a false construct, belief, or myth that persons with autism aren't social (Beardon, 2015). Many sources had socialised in the past (Brown, 2008) or/and did so now (e.g., Alex, Healthtalk, 2010e), and some wanted to do so in the future (e.g., Victoria, YouTube, 2013). The examples of the sociality of persons with autism described by Bagatell (2010) were described by some of the sources. This included preferring not to engage in small-talk (e.g., Brown, 2008), talking in monologues (e.g., Jarvis, 2008), and needing more alone time than the majority of the PNT (e.g., McCabe, 2003). Other examples of sociality were being brutally honest (e.g., Mark, Healthtalk, 2010d), only socialising on an intellectual level (e.g., Lawson, 2001), or preferring to engage in non-face-to-face social interactions (e.g., Alex, YouTube, 2014c). Conn, (2015) presented other examples of the sociality of persons with autism that were described by some of the sources. These included adults finding it easier to be friends with younger people (e.g., Mary, Healthtalk, 2010b), children with autism preferring to socialise with adults (e.g. Simone, 2010), and animals that were thought of as friends (e.g., Pottage, 2008).

My analysis of the data evidenced that the sources (e.g., Kerry, YouTube, 2014c) had, therefore, made friends and maintained friendships (Rowley et. al., 2012; Kuo et. al., 2013; Neysa, Carter, and Stephenson, 2014). It may have been that as stated by Chown (2012) friends were made and friendships were maintained as the sources had unknowingly, or/and out of necessity, gained an understanding of the PNT meaning of sociality (e.g., Oliver and Susie, Healthtalk, 2010f). With current attitudes to autism in a PNT-dominated society, for me, the necessity to do so lies with persons with autism if they are to survive and prosper (Milton, 2012).

From my perspective, viewing the sociality of the sources (e.g., Jarvis, 2008) through the external lens of the PNT had positioned their sociality as impaired and positioned them within the dis/human (Goodley and Runswick-Cole, 2016). I argue this is a false construct and the literature is actually referring to social behaviours that are observed less frequently in the PNT (e.g., Moss, 2014). There is little recognition in the literature that persons with autism are social (Ochs and Solomon, 2010). Ochs et. al., (2004, p147) stated, "Persons with autism need to be viewed not only as individuals in relation to other individuals, but as members of social groups and communities" and, therefore, their lived experience of sociality recognised. Membership of social groups and communities was a meaning described by several the sources (e.g., Arman, YouTube, 2012a). I argue, however, that the sources (e.g., Harvey, 2008) distrusted their sociality and encountered the disabling social barriers shown in Figure Four.

Having critically evaluated my themes in the light of my theoretical position on sociality, I now do so for friendship.

5.7 Friendship

Friendship in the literature was described as being ubiquitous in nature, a vital aspect of society (Mauk, 2011), and the human relationship of the greatest importance (Salmon, 2013). Similarly to sociality, I also concluded in Chapter Two that the meaning of friendship described by persons with autism aligns with

my theoretical position, i.e., presents possibilities for an enabling narrative of friendship.

My analysis of the data evidenced that the sources desired friendship (e.g., Debumaiya, YouTube, 2010) and some claimed to know that other persons with autism shared this desire (e.g., Simone, 2010). The findings of my research supported the claims made in the literature review in that friendships mattered and were important to the sources (e.g., EvieMay, YouTube, 2011). The sources described a desire for friendship that was wanted purely because it was important and of interest to them (e.g., Erinclem, YouTube, 2012c). The sources didn't regard friendship in any way as lesser or other and wanted to experience this phenomenon (e.g., Pears, 2004).

Most sources desired friendship with people (e.g., James, Healthtalk, 2010a) although some sources regarded objects (e.g., Tony, YouTube, 2012b) or animals (e.g., Pottage, 2008) as friends and desired friendships with them. All four academic disciplines defined friendship as being between people (Bagwell and Schmidt, 2011).

From my perspective, the desire to have objects (e.g., Debumaiya, YouTube, 2010) or animals as friends (e.g., Lawson, 2001) can be regarded as new information. For me, the assumption that friendships have to be with persons may have resulted from the focus of academia researching the PNT perspective of the meaning of this phenomenon (Mallet and Runswick-Cole, 2014), and the substantial amount of literature available. Authors have researched the capacity of animals to stimulate social interaction amongst persons as an enabler to friendship (Grandgeorge, 2012; O'Haire et. al., 2013). Research has also been conducted with persons with autism to assess the degree of interest shown in objects (Bruckner and Yoder, 2007; McDuffie, Lieberman, and Yoder, 2012). However, these authors didn't contextualise the object or animal as a friend. Davidson and Smith (2009, p912) researching autobiographies of persons with autism stated, "The dominant modern Western worldview fails to see the emotional power and potential of our relations with nonhuman others". As a result of researching from the PNT perspective, I argue there is little recognition

in the literature that persons can have friendships with objects (e.g., Harris, 2015) or animals (e.g., Simone, 2010).

I claim that different sources defined friendship in various ways. This was in terms of the size of friendship groups (e.g., Arman, YouTube, 2012a) and the sharing of activities and experiences (e.g., Richard, Healthtalk, 2014b). Whilst my findings identified that many of the sources supported the view that friendship was between two people (e.g., Brown, 2008), some had a wider definition of the number of persons with whom someone could form a friendship with, and this included groups of different sizes (e.g., Alex, Healthtalk, 2010e).

I posit that the element of reciprocity as a meaning of friendship was described by some of the sources. A number of sources defined friendship in terms of the sharing of activities (e.g., Sillygayboy, YouTube, 2011b). Sources regarded friendship as a meaningful part of their everyday activities (e.g., Lawson, 2001).

From my perspective, several sources recognised that there were qualities in people that did and didn't make good friends for them (e.g., EvieMay, YouTube, 2011c). A number of sources defined friendship through recognising the principles of right and wrong behaviour in the persons they had social relationships with (e.g., Simone, 2010). For some sources, the definition of friendship included the concept of trust (e.g., McCabe, 2003). To be a good friend for them meant having confidence in the honesty or integrity of a person (e.g., Lawson, 2001).

The definition of friendship for some sources included the ability to choose their friends (e.g., Simon, Healthtalk, 2010i). For me, the persons with autism in my study didn't relate belonging to a friendship group as representing a default position (e.g., Simon, Healthtalk, 2014f). To the contrary, the sources aspired to belong to friendship groups and valued their membership (e.g., Victoria, YouTube, 2013).

Many sources stated friendship made them feel happy (e.g., Simone, 2010) and that not having friends upset them (e.g., Pears, 2004). Friendship enabled

some sources to make an emotional connection with another person (e.g., Mary, Healthtalk, 2010). Other sources characterised friendship by the enjoyment they described (e.g., Brown, 2008). The function of enabling some sources to make a social connection with someone (e.g., Moss, 2014) supported the sharing of feelings and emotions (Holmes and Greco, 2011).

A number of sources made friends through sharing personal interests (e.g., Brown, 2008). These sources found that friends were useful to them and that they were useful to their friends, as they were able to share and maybe add to their knowledge of a personal interest (e.g., Victoria, YouTube, 2013). The sharing of personal interests includes the element of reciprocity, and this was a meaning described by these sources (e.g., McCabe, 2003). Sources (e.g., Nathan, YouTube, 2014a) engaged with communities in the form of shared personal interests.

Having evaluated my themes in the context of my theoretical interpretation of the key concepts of ToM, sociality, and friendship, I now do so for the social barriers of normalcy and ableism that I identified in my literature review.

5.8 Normalcy and ableism

In my literature review, I identified the social barriers of normalcy and ableism as the disabling concepts that persons with autism encounter in the meaning they describe of sociality and friendship. My analysis of the data evidenced that the meaning many sources described of their sociality and friendships was indicative of normalcy and ableism (e.g., Simone, 2010). For me, the only and correct meaning of these phenomena for many of the sources was to develop PNT social skills and personal qualities and use them to make friends and maintain friendships (e.g., Jarvis, 2008). I argue these sources regarded the PNT meaning of sociality and friendship as obtainable, the correct, and the only way of being (e.g., Harris, 2015).

From my perspective, ableism positioned the PNT meaning of sociality and friendship as perfection and the corporeal gold standard that some sources

thought they should strive to master (e.g., Stephen, Healthtalk, 2010m). I argue the label of autism cast the sources sociality, friends, and friendships in the category of 'inferior other', regardless of the success they had experienced in socialising, the friends they had made, or friendships they had maintained (e.g., Pottage, 2008).

This self-perceived failure to socialise, make friends, and maintain friendships compared to the PNT wasn't for the sources I claim the result of a lack of desire to do so (e.g., Kerry, YouTube, 2014c). Instead, the failure was attributed by many sources to their lack of PNT social skills and PNT personal qualities that didn't facilitate the mastery of PNT sociality (e.g., Mary, Healthtalk, 2010l). It was only this degree of mastery I argue that these sources believed would result in success in socialising, making friends, and maintaining friendships (e.g., McCabe, 2003).

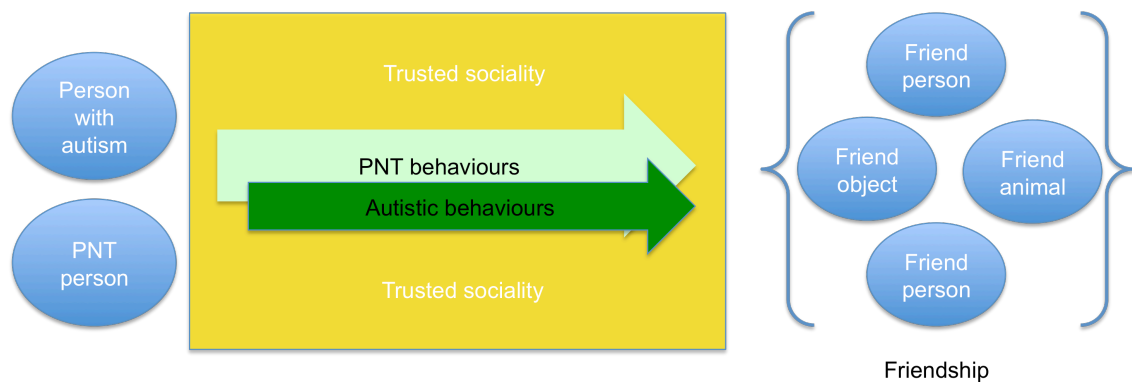
My analysis of the data also evidenced that the sources meaning of sociality was judged by them from the PNT perspective of perfection (e.g., Harris, 2015). I argue a successful outcome to the process of socialising, making friends, and maintaining friendships didn't re-cast the sources social skills and personal qualities from their perspective of inferior other to equating with the desired state of being (e.g., Victoria, YouTube, 2013) and my perspective is shared by other academics. Authors, e.g., Bauminger et. al., (2008b, p147) found that children with autism "perceived their friendships as less close, helpful and intimate" compared to that of the PNT. Children with autism were reported in other research to perceive their social competence to be lower than that of PNT children (Howard, Cohn, and Orsmond, 2006; Demopoulos, Hopkins, and Lewine, 2016). Neysa et. al., (2016) found that children with autism, despite having friends, perceived their friendships to be of a lower quality in terms of reciprocity and mutuality compared to their PNT peers. Some sources also described lower levels of social competence (e.g., Brown, 2008) and perceived their friendships to be of lower quality than their PNT peers (e.g., Ian, Healthtalk, 2010c).

I posit that some sources thought it was their responsibility to change themselves and master PNT social skills and personal qualities so that they could make their social approaches to the PNT understood (e.g., Stephen, Healthtalk, 2010m). This perspective that placed all the responsibility for achieving social acceptance on the person with autism (e.g., Richard, Healthtalk, 2014a), was identified as the social barriers of normalcy and ableism depicted in Figure Four.

The influence of internalised normalcy and ableism on the sources, the unconscious adoption of the ideas and prejudices of the PNT society, for me, cannot be disregarded. I argue the sources didn't have a conscious realisation that the only meaning of sociality they regarded as the only way of being, was that of the PNT (e.g., Jarvis, 2008). The sources had internalised the ideas and discriminatory practices of society that viewed them as faulty and in need of repair (e.g., Erinclem, YouTube, 2012c). In my data, this meaning was only occasionally questioned, communicated, or formally acknowledged (e.g., Brown, 2008). Internalised normalcy and ableism I claim may have contributed to the desire of the sources (e.g., Victoria, YouTube, 2013) to describe and master the same meaning as the PNT of sociality.

I argue that the disabling social barriers depicted in Figure Four were normalcy and ableism. The sources encountered these social barriers that positioned their sociality as distrusted (e.g., Catherine, Healthtalk, 2014d). I also argue that these social barriers need to be overcome so that the sources could trust their meaning of sociality, and, therefore, regard it as an integral part of the pathway that enables friends to be made and friendships to be maintained as depicted in Figure Five:

Figure Five



Broader constructions of sociality and friendships for persons with autism that argue for a range of possibilities across being human

From my perspective, overcoming normalcy and ableism requires the medical model of disability ideologies that I presented in my literature review to be questioned, challenged, and disrupted⁶³. O'Dell et. al., (2016, p169) stated, "The construction of autistic identities holds important insights for how to rethink, and extend, ideas associated with cognitive 'normalcy' (or 'ability') and difference". I further argue that it's the PNT meaning of sociality and friendship that has resulted in the construction of these disabling social barriers. The PNT, who hold the balance of power in society, therefore, for me, need to contribute to the deconstruction of normalcy and ableism.

I argue, therefore, that overcoming the social barriers of normalcy and ableism requires broader constructions of sociality and friendship. These broader constructions present possibilities for an enabling narrative of sociality and friendship for persons with autism that: 1) deconstructs the binary of autistic and PNT sociality and, therefore, advances a challenge to the dominant discourse on sociality and friendship for persons with autism; and 2) argues for a range of sociality and friendship possibilities across being human.

⁶³ I acknowledge that normalcy and ableism are also the medical model of disability ideologies. However, in the context of my research, they represent the social barriers that the sources encountered in the meaning they described of sociality and friendship.

To summarise for me, there is no such thing as the binary of autistic sociality and PNT sociality. I claim as shown in Figure Five, the outcome of my research is there is **one sociality** that represents a range of possibilities across being human that enables friends to be made and friendships to be maintained by both persons with autism and the PNT. There are, however, behaviours that are more likely to be observed in persons with autism than in the PNT that overlap between the two neurotypes. Recognising this overlap of behaviours will contribute to overcoming the disabling social barriers of normalcy and ableism and resolving the conundrum that despite the sociality of persons with autism, the positive experience of friendship that they desire and enjoy is difficult for them to achieve.

Having discussed my findings in relation to my literature review, I now summarise their significance in terms of my theoretical position.

5.9 The significance of my findings

5.9.1 Describing the meaning of sociality and friendship

The sources desired to socialise, make friends, and maintain friendships (e.g., Moss, 2014) and different sources defined friendship in various ways (e.g., Mary, Healthtalk, 2010I). The persons with autism in my study understood how to make friends (e.g., Victoria, YouTube, 2013) and had had successful friendship experiences (e.g., Ben, YouTube, 2012b). These positive experiences of friendship had enabled sources to make an emotional connection with a person (e.g., Mary, Healthtalk, 2010I), object (e.g., Harris, 2015), or animal (e.g., Pears, 2004) and had made them happy (e.g., Richard, Healthtalk, 2014e). Some sources also aspired to socialise and make friends in the future (e.g., Harvey, 2008).

Some sources claimed to know other persons with autism described the same meaning from sociality and friendship and that they too wanted to socialise, make friends, and maintain friendships (e.g., Alex, YouTube, 2014a). Although sources had had positive sociality and friendship experiences (Brown, 2008),

they described many more negative ones (e.g., Mary, Healthtalk, 2010l). Sources had frequently failed to socialise, make friends, and maintain friendships and this resulted in negative emotional states (e.g., Catherine, Healthtalk, 2014g).

The sources, therefore, for me, described meaning from their lived experience of sociality and friendship (e.g., Brown, 2008). This meaning in support of my theoretical position of an enabling narrative of sociality and friendship for persons with autism needs to be valued as knowledge and, therefore, calls for broader constructions of these phenomena.

5.9.2 Misunderstandings of social behaviours

From my perspective, one significant area of perceived impairment identified from the data and described by many of the sources (e.g., Harris, 2015), was in the social approaches or behaviours made by them in socialising, with the aim of making friends and maintaining friendships. It is these behavioural approaches to the PNT I claim that determined the success and failure of the sources in experiencing these phenomena. I claim that misunderstandings and misinterpretations of these social approaches by the PNT (e.g., Pottage, 2008) often occurred due to the disabling social barriers depicted in Figure Four that resulted in the failure of sources to make friends or maintain friendships.

This disadvantaged outcome of persons with autism (e.g., Lawson, 2001) is, I posit, indicative of the PNT dominated society that they inhabit. These social approaches, I argue, aren't exclusive to persons with autism but are behaviours that are more frequently observed in persons with autism than the PNT (e.g., Ian, Healthtalk, 2010c). For me, it's of critical importance that these social behaviours are understood as representing a range of possibilities across being human, as depicted in Figure Five, as they may represent the first attempt at interaction with someone who has the potential to become a friend and to maintain a friendship with. Such broader constructions of sociality support my theoretical position as it supports my claim that there is **one sociality** that

enables friends to be made and friendships to be maintained by both persons with autism and the PNT.

5.9.3 The medical model of disability ideology

As I identified in Chapter Two, the dominant discourse in the literature is that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2011; Locke, Kasari, and Wood, 2014). For me, the findings of my research are significant in that they questioned, challenged and have the potential to disrupt this dominant discourse of medical model of disability ideology that I have rejected. These PNT beliefs, that were adopted by the sources I posit were disabling, had little meaning for them, and were socially oppressive as they communicated to the sources that impairment was synonymous with disability. Sources distrusted their meaning of these phenomena despite the successes they had experienced in socialising and friendship (e.g., Erinclem, YouTube, 2012c) and those they anticipated in the future (e.g., Victoria, YouTube, 2013).

From the medical model of disability perspective that I reject, the symptoms of abnormal or deficient sociality and friendship of the sources (e.g., Simone, 2010), needed to be treated and cured, to align with the wellness represented by the PNT meaning of these phenomena. The result was only one trusted meaning of sociality, the PNT sociality pathway shown in Figure Four, for persons with autism in the study (e.g., Harvey, 2008). This medical model of disability ideology also positioned sources, for me, as lesser, other, and distrusted in terms of the meaning they described of sociality and friendship (e.g., Richard, Healthtalk, 2014a). I argue that by questioning, challenging, and disrupting the medical model of disability ideology, the conundrum that I identified can be resolved, i.e., that despite the sociality of persons with autism, the positive experience of friendship that they desire and enjoy is difficult for them to achieve. Resolving this conundrum will result in the deconstruction of the binary of autistic and PNT sociality and the recognition that there is **one sociality** that enables friends to be made and friendships to be maintained by both persons with autism and the PNT as shown in Figure Five.

5.9.4 Overcoming social barriers

My findings identified the social barriers of normalcy and ableism shown in Figure Four. These social barriers needed to be overcome to allow the sources to trust their meaning of sociality and, therefore, to regard it as an integral part of the pathway that enables friends to be made and friendships to be maintained as depicted in Figure Five. From my perspective, the responsibility for overcoming social barriers was regarded by the sources (e.g., Moss, 2014) as being their responsibility and theirs alone, i.e., sources thought it was for them to change to adapt their social skills and develop personal qualities to mirror those of the PNT and describe their meaning (e.g., Stephen, Healthtalk, 2010m).

From my perspective, sources didn't expect the PNT to change, deviate from their meaning or position of ontological security, or to develop social skills or personal qualities that mirrored theirs (e.g., Simone, 2010). I argue that to overcome these social barriers what is required is the disruption of normalcy and ableism. To facilitate this process, the PNT who have constructed and perpetuated these social barriers, need to acknowledge and communicate to the sources that their sociality can be trusted and represents a range of possibilities across being human. This communicative act by the PNT may, I posit, enable the sources to trust their meaning of sociality and, therefore, to regard it as an integral part of the pathway that enables friends to be made and friendships to be maintained as illustrated in Figure Five.

For me, overcoming the barriers of internalised normalcy and ableism presents a particular challenge. I argue that this unconscious adoption of the prejudicial ideas of society needs to be challenged. This requires the influencing and reshaping of the attitudes of the PNT who hold the balance of power in society and influence the politics of knowledge production.

5.9.5 Contributing to knowledge

My findings are significant in that they address the gap in recorded knowledge that I have identified, i.e., in autism research, there was a gap in knowledge regarding the meaning of sociality and friendship for persons with autism that described their lived experience from their perspective.

In terms of contributing to knowledge, I argue my findings are significant in that they describe the meaning that persons with autism made from sociality and friendship as depicted in Figure Four and are trustworthy (Lincoln and Guba, 1985). Sociality and friendship were desired and valued by the sources (e.g., Tony, YouTube, 2012b). The disabling social barriers of normalcy and ableism were internalised by the persons with autism in my study (e.g., Jarvis, 2008). For the sources the meaning described by the PNT of sociality was the only trusted pathway to making friends and maintaining friendships (e.g., Victoria, YouTube, 2013). I argue that what is required, as depicted in Figure Five, is the recognition that there is **one sociality** that enables friends to be made and friendships to be maintained by both persons with autism and the PNT. Achieving this requires the deconstruction of the binary of autistic and PNT sociality that will contribute to resolving the conundrum that I identified in the literature.

Having discussed the significance of the findings the next sections of this chapter consider the limitations of my research, the dissemination of my findings, and opportunities for further inquiry.

5.10 Limitations of my research

I have theorised opportunities for further research based on the limitations identified from my findings. The limitations of my research are examined in terms of my methodological choices, my commitment to emancipatory disability research, and my theoretical position. I acknowledge that a limitation in research can at times be re-interpreted as a possibility for the advancement of knowledge.

Whilst the findings of my qualitative inquiry are relevant to the persons with autism in my study, they are, as for all qualitative research, unable to be generalised to other populations (Whittemore, Chase, and Mandle, 2001). The findings may, therefore, be unique to the persons with autism in my study. My data collection was from thirty-one video blogs and online interviews and ten autobiographical accounts published in books. I recognise that this is a relatively small sample that may not be taken seriously by other academic researchers and professionals. My findings also don't provide any statistical evidence that is often used to bring about changes to educational practices (Griffin, 2004) through discovering and verifying trends in data.

In Chapter Three, my analysis of methodology led me to question whether I could undertake research that was aligned with the emancipatory disability research paradigm. I argue that my qualitative enquiry was *influenced* by emancipatory disability research principles and demonstrated my commitment to this research paradigm. My work can emancipate by advancing a challenge to the dominant discourse that persons with autism find it difficult to make friends and maintain friendships due to a lack of social skills (e.g., Frankel and Whitham, 2001; Locke, Kasari, and Wood, 2014). The outcome of my research I further argue could be viewed as improving the lives of persons with autism. My ideas for further research that I now discuss include approaches that would allow me to further develop my commitment to this research paradigm.

5.11 Ideas for further research

5.11.1 Replicating the study

The findings of my research are only true for the persons with autism in my study. They cannot be generalised to other populations of persons with autism (Whittemore, Chase, and Mandle 2001). It may be that other persons with autism describe the same meaning from the phenomena of sociality and friendship as the sources. Conversely, it may be that my findings are unique to the sources in my study and don't typify the meaning that persons with autism describe of sociality and friendship. O'Dell et. al., (2016, p168) stated, "It is

clear that people with autism don't speak with one voice. Anything less would be fundamentally insulting and harmful to people with autism themselves, and to the myriad knowledge and experience they mobilise in the field of autism".

Replicating the study using other YouTube video blogs, online interviews, and autobiographical accounts in books could enable the meaning that other persons with autism describe of their sociality and friendship experiences to be presented. Should the same findings be described from replicating my study, this may further contribute to overcoming the social barriers of normalcy and ableism and realising broader constructions of sociality and friendship as shown in Figure Five.

The sources used in my research all identified with the labels of HFA or AS. One further area of research may be to replicate my study with persons with autism that identify with this label but don't meet the criteria for HFA or AS. This would include persons with an intellectual disability.

5.11.2 Alternative research approaches

My qualitative inquiry used online data sources and books. However, I have acknowledged that other data sources could have been used, e.g., interviews, surveys or case studies with persons with autism. These approaches align more with my commitment to the emancipatory disability research paradigm and support my theoretical position as they provide the opportunity to co-construct data with the participants. A case study with fewer participants may allow a more in-depth inquiry into the meaning of sociality and friendship for persons with autism to be undertaken.

5.11.3 Asking different research questions

Now that the findings of my research are known, I can reflect that there may have been better or more interesting research questions to ask. My literature review identified that some persons with autism desired or described friendship with objects (e.g., Williams, 1992; Slavin, 2015) or with animals (e.g., Gardner,

2008 Carlisle, 2015). Four sources desired to socialise with objects (Pottage, 2008; Debumaiya, YouTube, 2010; Tony, YouTube, 2012b; Harris, 2015) or with animals (Lawson, 2001; Pears, 2004; Pottage, 2008; Simone, 2010). More focused research questions may have identified these as meanings for more of the sources. This may have involved using different search terms when identifying YouTube blogs, online interviews and autobiographical accounts published in books.

Another more interesting question to ask may have been “What meaning do sources think other persons with autism describe of sociality and friendship?” My literature review didn’t identify any instances of persons with autism being asked if they thought other persons with autism shared their desire to socialise, make friends, and maintain friendships. This question presents a particular challenge to the theoretical construct of ToM. The extent to that persons with autism are able to impute mental states in others, may need to be questioned, challenged, and disrupted to identify any disabling concepts that may be being imposed on them.

Other research questions could address how internalised normalcy and ableism have embedded themselves in the meaning of sociality and friendship for persons with autism. Potential questions include, “Why do persons with autism only regard the PNT meaning of sociality as the trusted pathway to making friends and maintaining friendships?” or “Why do persons with autism aspire to master the PNT meaning of sociality and friendship?” Answering these question may contribute to overcoming the social barriers identified from my research. If normalcy and ableism are to be overcome, I argue these questions should be asked not just of persons with autism but of the PNT as well. This will allow those that have constructed normalcy and ableism to contribute to its deconstruction.

5.11.4 Other social theories

A finding from the theme of desire for sociality and friendship that I hadn’t identified from my literature review, was that some sources claimed to know

that other persons with autism desired to socialise, make friends, and maintain friendships (e.g., Simone, 2010). A number of sources also wanted to help and support other persons with autism fulfil their need for sociality and friendship (e.g., Nathan, YouTube, 2014b). These sources had described strategies that they thought would help them to socialise, and make friends and recommended that other persons with autism use them to have successful socialising and friendship experiences (e.g., Moss, 2014).

From my perspective, these supportive acts resulted in no personal gain for these sources. In addition, it was selfless and implied an understanding of them of what other persons with autism needed to do to fulfil their desire for sociality and friendship. This meaning described of sociality and friendship may be indicative of the theory of Empathy-Altruism or an empathic concern that produces altruistic motivation (Batson et. al., 1989). These sources, therefore, wanted to help other persons with autism, whom they perceived to be in need of or desired sociality and friendship, out of genuine concern for the well being of that individual (e.g., Simon, Healthtalk, 2010i).

A finding from the theme of success and failure that I hadn't identified in my literature review, was, for me, the desire of many sources for the PNT to feel secure in the meaning they described of sociality and friendship (e.g., Stephen, Healthtalk, 2010m). There was a general absence of challenge of the sources to the PNT status quo, as to how to socialise, make friends, and maintain friendships (e.g., Jarvis, 2008). This finding is indicative of the theoretical construct of ontological security, i.e., "a centrally firm sense of [one's] own and other people's reality and identify" (Woolley, 2007, p176). Again, as with the theory of Empathy-Altruism (Batson et. al., 1989), I didn't identify this theoretical construct from my literature review as having been the subject of academic research.

Another finding that I hadn't identified from my literature review was that four sources desired to socialise with objects and regarded them as friends (Pottage, 2008; Debumaiya, YouTube, 2010; Tony, YouTube, 2012b; Harris, 2015). From my perspective, this meaning of sociality and friendship may be

indicative of object-personality synaesthesia. Synaesthesia can be defined as “a neurodevelopmental condition in which a sensation in one modality triggers a perception in a second modality” (Baron-Cohen, et. al., 2013, p1). These authors concluded that synaesthesia may occur in some persons with autism. Smilek et. al., (2007) reported a case study in which an individual described household objects as having “rich and detailed personalities” that they termed, “object-personality synesthesia”⁶⁴ (2007, p981). Similarly, Prince-Hughes (2004, p50), stated, “I could feel the personalities of the rocks, the trees the grass, the hills”. There is, therefore, the possibility of object friendship for persons with autism when they also experience object-personality synesthesia. Baron-Cohen et. al., (2013) concluded the prevalence of synaesthesia was greater in persons with autism than the PNT, and that the two conditions may share some fundamental attributes.

Researching empathy-altruism (Batson et. al., 1989), ontological security, (Woolley, 2007) and object-personality synaesthesia (Smilek, et. al., 2007) could, therefore, add to the existing body of knowledge as to the meaning of sociality and friendship for persons with autism. Having discussed the limitations of my research and identified opportunities for further research, I now turn my attention to how the completion of my thesis has informed and shaped my researcher positionality.

5.12 Reflections on researcher positionality

My researcher positionality is that knowledge arises from the reflection on and communication of the lived experience. A social oppression theory of disability encapsulates my interpretation of the nature of being (Oliver, 2006). My ethics are based on the underlying principles of respect, beneficence, non-maleficence, and justice (Bishop, 2009). My ethical position is embedded in my ontological position with a primary need to address inequalities in the meaning described of sociality and friendship of persons with autism.

⁶⁴ Synesthesia is an alternative spelling of synaesthesia.

The completion of my research hasn't changed my researcher positionality but has strengthened my ontological position. I now have a deeper and broader understanding of the social barriers of normalcy and ableism and the impact they can have on the lived experience of persons in a minority group, such as the sources in my study. My awareness of the subtleties of how social relations are practised has been magnified. I'm more aware of the social barriers that are present in society and how they have been created by the PNT. I'm also more aware of their impact on the persons with autism in my study that has prevented them from trusting their meaning of sociality. I have come to realise that the attitudes of the PNT that result in social barriers in society may not have resulted from a conscious realisation. It may merely be an integral part of how social relations are practised by the PNT majority, in their position of power, with a corresponding lack of awareness by them as to any negative connotations.

Writing my thesis has contributed to the development of my critical understanding of the range of possibilities across being human of the meaning of the same phenomena. From my perspective, the PNT who predominantly hold the balance of power in a social group or friendship may describe one meaning of sociality and friendship, and the person with autism in the same relationship another. The PNT may, for me, regard their meaning as trusted, whilst the person with autism may feel that as a result of social barriers, that the meaning they describe is one of lesser or other. I now have a deeper understanding of the inequalities that exist for persons with autism in society and the disabling medical model of disability ideology imposed upon them that places them at a disadvantage. I'm also more aware of the resultant social barriers that need to be overcome to address this disadvantage of persons with autism in our PNT society.

Having discussed the significance of the findings of my research, its limitations, opportunities for further research, and reflected on my positionality and theoretical position, I now critique how my findings can inform professional practice.

5.13 Informing professional practice

5.13.1 Introduction

The professional doctoral programme requires a critical consideration of the significance of the outcome of the research for my own or others' professional practice that I now examine. The outcome of my research is there is **one sociality** that represents a range of possibilities across being human that enables friends to be made and friendships to be maintained by both persons with autism and the PNT.

As I presented earlier in my literature review, sociality has allowed humans to survive and prosper and is also a pivotal factor in the general well being of individuals (Haslam et. al., 2009). Similarly, friendship is regarded as a vital aspect of society (Mauk, 2011). The findings of my research supported this discourse in the published literature, i.e., the sources described meaning from their sociality and friendship experiences and achieving a positive experience of these phenomena mattered to them. However, from my perspective, the sources in my study frequently experienced a disadvantaged outcome in terms of their sociality and friendship experiences (e.g., Pears, 2004) as a result of the PNT society that they inhabit⁶⁵.

Whilst I advocate the possibility of enabling narratives of sociality and friendship to improve the outcomes of persons with autism I argue this isn't just a matter for the individual. To overcome this disadvantage of persons with autism requires enabling public policies and practices to be adopted and implemented by the state.

Government policy sets out what the state aims to achieve with respect to a particular social and/or political aspect of society. A Government report published in 2016 stated that, in developing policy "Successive Governments

⁶⁵ Throughout section 5.13, references to the disadvantaged outcome that persons with autism experience are based on my perspective of their lived experience as conceptualised by the theory of disadvantage (Beardon, 2017) that I examined in Chapter Two that forms part of my theoretical position.

have pledged to improve outcomes for people with autism” (Great Britain, Parliament, House of Commons, 2016, p3) In achieving this aim, Government policy will, therefore, in theory, contribute to overcoming the disadvantage that persons with autism experience in our PNT dominated society including that of sociality and friendship. I now present a summary of current Government policy on autism in England and where applicable the UK (Great Britain, Parliament, House of Commons, 2016)⁶⁶.

5.13.2 Government policy on autism

The government introduced in 2009 the first ‘disability-specific’ piece of legislation in the UK, the Autism Act (Great Britain, 2009). This Act aimed to “make provision about meeting the needs of adults with autistic spectrum conditions” (Great Britain, 2009, p1) and, therefore, to address the disadvantaged social, economic, and health outcomes of persons with autism (Clark, et. al., 2014). The Autism Act 2009 (Great Britain, 2009) required: 1) an autism strategy to be published to enable the needs of persons with autism to be met; and 2) statutory guidance on implementing the strategy.

The autism strategy originally published in 2010 (Great Britain, DoH, 2010) and revised in 2014 entitled, *Think autism* emphasised a greater focus on awareness of autism in organisations and communities (Great Britain, DoH, 2014⁶⁷). The statutory guidance, updated in 2015 made a similar commitment (Great Britain, DoH, 2015).

These organisations are principally service providers that include (mental) health and care services, education, employment, the welfare, and criminal justice systems. I now examine how the outcome of my research that there is **one sociality** that represents a range of possibilities across being human that

⁶⁶ Healthcare is a devolved matter. The administrations of Scotland, Wales, and Northern Ireland have set their own policies on autism. Within the confines of my thesis it wasn’t possible to consider all the policies of the devolved administrations.

⁶⁷ In January 2016, the Government published the *Think autism* progress report (Great Britain, DoH, 2016). The report set out a number of new actions to achieve the challenges identified in the 2014 strategy.

enables friends to be made and friendships to be maintained by both persons with autism and the PNT can contribute to my own and others' professional practice. I have chosen to address the professional practices of parenting, mental health, education and academic writing⁶⁸.

5.13.3 Government policy on parenting

Research completed for the NAS (Bancroft et. al., 2012) of nearly 3,000 children and adults with autism found that⁶⁹:

- 22% of young persons had no friends at all
- 59% of adults with autism found it hard to make friends
- 65% of adults with autism would like to have more friends
- 70% of adults with autism said that with more support they would feel less isolated.

These statistics show that as for the sources in my study (e.g., McCabe, 2003) and for my son, persons with autism experience a disadvantaged outcome in terms of their sociality and friendship experiences.

As I wrote in Chapter One, the origin of my interest in researching sociality and friendship is as the parent of my son who has the label of AS. It wasn't until 1997 that the UK Government became concerned with family and, therefore, parenting policy that had previously been regarded this as a private matter. In 2006, the Labour Government committed to improving parenting provision

⁶⁸ I recognise that there are other areas of professional practice that my research could inform. However, it wasn't possible within the confines of my thesis to address them all. I, therefore, chose to explore those that I related to the most.

⁶⁹ Whilst comparative figures for all the outcomes cited above aren't available, 4% of children without autism had been excluded from school and the NEET (not in education, employment or training) rate is more than double that in the general population (Bancroft et. al., 2012).

laying the foundations of the Parenting Early Intervention Programme (PEIP) (Cullen, 2016) and this commitment was strengthened by the 2010 coalition Government. Subsequently, the Conservative Government has continued the commitment to provide universal parenting support through the provision of parenting classes for all parents who would like it (Cullen, 2016). However, as of 2017, these parenting classes were now reported as being “in an uncertain position with no further information published to date” (Great Britain, Social Mobility Commission, 2017, p7).

The Government report, *Helping parents to parent* published in February 2017 stated amongst its conclusions that research suggests: 1) “that parenting has a significant influence on children’s outcomes; 2) public policy can have an impact on parenting behaviours; and 3) the most successful parenting interventions appear to have a focus on equipping parents with a greater understanding of child development” (Great Britain, Social Mobility Commission, 2017, p4). Based on these findings I concluded that regarding the professional practice of myself and other parents, we have the opportunity to positively influence our child’s sociality and friendship experiences.

Research evidences that a high-quality parenting environment makes a positive contribution to the developmental outcomes of a child and in particular to their physical, emotional, and social well being (Asmussen, 2011). Other studies have also found that parents can significantly influence the social competence of their children (Miller and Coll, 2007). Studies of parents of children with autism have concluded that in their role as primary care givers, parents support the personal and social development of their children (Lasgaard et. al., 2009). Parental support was found by these authors to have helped their children with autism sustain a social network and had a positive effect on their self-esteem. Other research has evidenced that a positive parental attitude to a child with disabilities, including autism, has had a positive impact on the sociality of the child (Benson, 2013). Based on these findings, the outcome of my research can contribute to the professional practice of parenting as follows:

Recommendation: That parents communicate to their children alternative possibilities for enabling narratives of sociality and friendship, to facilitate their socialising, making friends, and maintaining friendships. I intend that my own parenting practice is also framed this way.

One in ten children who access child and adolescent mental health services (CAMHS) have autism (NAS, 2017). In addition, although mental illness is more common in persons with autism than in the general population this aspect is often overlooked (Galanopoulos et. al., 2014). In the following section, I explore how the outcome of my research can contribute to professional practice in mental healthcare.

5.13.4 Government policy on mental health

NAS research has evidenced the disadvantaged outcome of persons with autism regarding mental health (Galanopoulos et. al., 2014):

- More than 70% of persons with autism experience mental illness
- Anxiety disorders are very common. Approximately 40% have symptoms of at least one anxiety disorder at any given time compared to 15% of the general population
- Obsessive-compulsive disorder and depression is more common in persons with autism than the general population
- Although mental illness is more common in persons with autism than in the general population this aspect is often overlooked.

In response to these and other mental health statistics, in March 2015 the Government published a consultation paper entitled, *No voice unheard no right ignored – a consultation for people with learning disabilities, autism and mental health conditions* (Great Britain, DoH, 2015a). This consultation included the Mental Health Act Code of Practice (Great Britain, DoH, 2015b) that supports the Mental Health Act 1983 (Great Britain, 1983) and considers how the rights

and choices of people can be strengthened. In its' response to the consultation, the Government stated (Great Britain, DoH, 2015c, p3):

our aim is that people lead as fulfilling and independent lives as they can, and that they have the support to live independently when possible. This requires a step change. Services, and wider society, should first and foremost see the person and their potential.

The Government stated that this role would involve for professionals in mental health “listening to people” and “understanding their wishes and desires” (Great Britain, DoH, 2015c, p19). In January 2017, the Government outlined plans to improve support for people who experience mental illness in England (GOV.UK, 2017). This objective that is focused on children, aims to transform attitudes to mental health in society.

In support of this aim, there is a growing body of work that claims that social relationships have a positive influence on all aspects of a person's health (Jeten, Haslam, and Haslam, 2012). Cooper, Smith, and Russell (2017, p1) concluded that having a positive social identity improved the mental health of persons with autism and that “Clinical approaches should aim to facilitate development of positive autism identities.” Other research suggests that social isolation is a key factor in mental health difficulties experienced by persons with autism who wish to socialise (Jones, Zahl, and Huws, 2001; Bagatell, 2007; Ratcliffe et. al., 2015). Based on these findings, the outcome of my research can contribute to the professional practice of mental health professionals as follows:

Recommendation: That all mental health workers receive awareness training on the positive influence of socialising, making friends, and maintaining friendships on the mental health of persons with autism.

As I introduced in section 5.13.2, the Autism Act 2009 is the cornerstone of Government policy on autism and was originally drafted to include adults and children (NAS, 2017). However, prior to the Bill receiving royal assent, the Government decided it would be better to “help children on the autism spectrum in other ways” (NAS, 2017, p1). I now examine Government education policy in

England of relevance to my research, and I begin my presenting statistics that highlight the disadvantaged outcome of children with autism in school.

5.13.5 Government policy on education and autism

NAS research has also evidenced the disadvantaged outcome of persons with autism in education. A survey of around 1,000 parents, carers, children, and young people with autism found that (Moore, 2016):

- Pupils with autism were more than four times likely to be excluded from school than pupils without SEN
- When asked what would improve their experience of school, two-thirds of children and young people with autism themselves said a better understanding of autism by teachers
- 60% of children and young people with autism said the worst thing about school, from their perspective, were teachers who don't understand autism. The second worst thing was not having friends
- Only 50% the children and young persons with autism felt happy, and 33% felt included at school.

From these statistics increasing the awareness of teaching staff and other children of autism and in particular of the desire of children with autism to socialise, make friends, and maintain friendships would help to address these disadvantaged outcomes.

The vision of the Government for educating children with special educational needs and disabilities is “the same as for all children and young people – that they achieve well in their early years, at school and in college, and lead happy and fulfilled lives” (Great Britain, DoE and DoH, 2015 p11). The Children and Families Act 2014 (Great Britain, DoE, 2014) introduced the special educational needs and disability (SEND) support system that covers education, health, and

social care. Statutory guidance was published in 2015 and requires Local Educational Authorities and schools to “focus on inclusive practice and removing barriers to learning” (Great Britain, DoE and DoH, 2015, p20). The guidance also stated, “Children and young people with SEN or disabilities are to achieve their ambitions and the best possible educational and other outcomes” (Great Britain, DoE and DoH, 2015, p24).

These other outcomes could be interpreted as positive sociality and friendship experiences for children with autism. The use of a peer network in schools has been shown to increase the social engagement of students with autism (Hockman et. al., 2015; Sreckovic, Hume, and Able, 2017). Peer mentoring in Higher Education has also evidenced a better outcome of students with autism in terms of their general well being (Siew et. al., 2017). In this study, socialisation was regarded by the participants as one of the positive outcomes of the study with a number describing the new friendships they had made and the positive impact on their academic performance. Other studies have reached a similar conclusion (Macleod and Green, 2009; Knott and Taylor, 2013). Based on these findings the outcome of my research can contribute to the practice of education professionals and in increasing the understanding of autism in PNT children as follows:

Recommendation: That all education professionals receive awareness training for children with autism on: 1) the importance of social engagement and friendship to facilitate better outcomes; 2) the range of possibilities for sociality and friendships; and 3) the benefits of peer networks with PNT children.

Recommendation: That the importance of socialising and friendship to children with autism (including the many forms this may take) be communicated to PNT children.

Having considered the professional practice of service providers, I now reflect on how the outcome of my research can inform the professional practice of academic writing.

5.13.6 The practice of academic writing

The outcome of my research may also contribute to the professional practice of academic writing. Articles on autism published in academic journals, included in the introduction a summary of diagnostic criteria or a medical model of disability understanding of autism (Jones and Meldal, 2001; Daniel and Billingsley, 2010; Locke et. al., 2010; Solomon, Bauminger, and Rogers, 2011; Hotton and Coles, 2016). The introduction, therefore, positioned the author's work in the medical model of disability ideology and presented this as the context for their research from the outset of their paper. This resulted in, for me, a disadvantaged view of persons with autism being communicated to the reader from the beginning of the article, even prior to the focus of enquiry being introduced (Carter et. al., 2004; Baron-Cohen, 2005; Howard, Cohn, and Orsmond, 2006; Kasari et. al., 2011; Hotton and Coles, 2016). This context may have little meaning or relevance to the persons with autism referred to in the research.

From my perspective, academic writing needs to acknowledge that persons with autism described meaning from their sociality and friendship experiences. As shown in Figure Five I argue there is **one sociality** that represents a range of possibilities across being human and enables friends to be made and friendships to be maintained by both persons with autism and the PNT. There are, however, behaviours that are more likely to be observed in persons with autism than in the PNT that overlap between the two neurotypes. Any academic writing that I undertake in the future will aim to reflect this meaning of these phenomena that presents possibilities for an enabling narrative of sociality and friendship of persons with autism. I also hope that other academics will adopt this perspective in their writing.

Academic writing wasn't a professional practice that I had identified that my research could inform at the start of my thesis. This medical model of disability practice is one I have gradually become aware of, as my professional doctorate has progressed. I argue it is necessary to question, challenge, and disrupt these academic writing practices. As concluded by Davidson and Orsini (2010, p133), "Researchers must continually question experience and expression of

emotion in all senses and spaces, including, and perhaps especially, what counts as 'normal' in mainstream society". Based on these findings, the outcome of my research can contribute to the professional practice of academic writing as follows:

Recommendation: That (through my own dissemination) academics present possibilities for an enabling narrative of sociality and friendship of persons with autism.

Having critically considered the significance of the outcome of the research for my own and others' professional practice, I now return in my discussion chapter to my research questions and provide answers to them.

5.14 Summary

At the start of my thesis, I proposed to make a contribution to knowledge by answering the following research questions. My analysis of the data evidenced the following answers:

1. What meaning do persons with autism describe of the phenomena of sociality and friendship? The sources described meaning from sociality and friendship. The sources desired to socialise, make friends, and maintain friendships and different sources defined friendship in various ways. The persons with autism in my study understood how to make friends and had had successful friendship experiences. These positive experiences of friendship had enabled sources to make an emotional connection with a person, object, or animal and had made them happy. Some sources also aspired to socialise and make friends in the future.

Some sources claimed to know other persons with autism described the same meaning from sociality and friendship and that they too wanted to socialise, make friends, and maintain friendships. Although sources had had positive sociality and friendship experiences, they described many more negative ones.

Sources had frequently failed to socialise, make friends, and maintain friendships and this resulted in negative emotional states.

In wanting to socialise, make friends, and maintain friendships, the sources described from their perspective a meaning of sociality that was distinct from that of PNT persons that I labelled as autistic sociality. The sources regarded PNT sociality as the only trusted pathway to making friends and maintaining friendships that was correct, obtainable, and preferred. For the sources, this recast their meaning of sociality and friendship as inferior, other, and lesser.

2. What barriers do persons with autism encounter in experiencing sociality and friendship? These were the disabling social barriers of normalcy and ableism. Despite their successes in making friends and maintaining friendships, the sources distrusted their sociality. The PNT meaning of sociality had been internalised by the sources as distinct from their autistic sociality, the correct, obtainable, trusted, and only way of being. The sources didn't appear to have a conscious realisation of the prejudicial ideas of society, and these were naturally embedded in them. For the sources, describing the PNT meaning of sociality and friendship and its mastery was paramount. This meaning wasn't questioned, communicated, or was required to be formally acknowledged by the sources.

3. How do persons with autism see these barriers being overcome? The task of overcoming these social barriers was regarded by the sources as being their responsibility alone, and could only be achieved by developing and mastering PNT social skills and personal qualities. Sources didn't expect the PNT to gain an understanding of their sociality or to change or deviate from their meaning or position of ontological security.

To the contrary, I argue it is the PNT meaning of sociality and friendship that has resulted in the construction of these disabling social barriers. The PNT, who hold the balance of power in society, therefore, need to contribute to the deconstruction of normalcy and ableism. I argue, therefore, that overcoming the social barriers of normalcy and ableism requires broader constructions of

sociality and friendship. These broader constructions present possibilities for an enabling narrative of sociality and friendship for persons with autism that: 1) deconstruct the binary of autistic and PNT sociality, and, therefore, advances a challenge to the dominant discourse on sociality and friendship for persons with autism; and, 2) argues for a range of sociality and friendship possibilities across being human. There is, therefore, **one sociality** that enables friends to be made and friendships to be maintained by both persons with autism and the PNT.

In summary, I conclude that my findings are trustworthy (Lincoln and Guba, 1985), and I have provided answers to my research questions that addressed this gap in the recorded knowledge. The next and final chapter, the conclusion, presents a synthesis of my thesis. The conclusion aims to make insightful connections between the chapters and presents and supports my claim to the contribution of knowledge that I argue my research has made.

6 Chapter Six: Summary and conclusions

In Chapter Six, I critically reflect on the research process, its outcomes and the implications, from my perspective, for the meaning of sociality and friendship for persons with autism. I commence this final chapter with a summary of my thesis.

6.1 Summary of my thesis

The origins of my focus of enquiry are rooted in my role as the mother of a son with AS. My observations of my son's lived experience present me with a conundrum, i.e., that despite his sociality, the positive experience of friendship that he so desires and enjoys is difficult for him to achieve. I believe my son experiences a binary of autistic and PNT sociality, i.e., the sociality of his PNT peers enables friends to be made and friendships to be maintained whilst his autistic sociality fails to do so. From this conundrum, I identified the gap in knowledge that I wished my research to inform, the meaning of sociality and friendship for persons with autism from their perspective.

In the literature, there are different understandings of autism, and I explored each of these to enable me to define my theoretical position. From my review, it's clear that, first, researching the friendship and sociality of persons with autism from their perspective has received limited attention from the academic community (Neysa, Carter, and Stephenson, 2014). Second that the dominant understanding of autism in our society is based on the medical model of disability ideology that: 1) privileges PNT sociality and friendship over that of persons with autism (Rowley et. al., 2012); 2) positions persons with autism as deficient, impaired, and lacking sociality in comparison to the PNT (Dempolous, Hopkins, and Lewine, 2016) and; 3) doesn't recognise the meaning of sociality and friendship described by persons with autism as knowledge (Broderick, Reid, and Weatherley-Vale, 2008).

From my perspective, this medical model of disability understanding of autism has resulted in the binary of autistic and PNT sociality, i.e., PNT sociality

enables friends to be made and friendships to be maintained whilst autistic sociality doesn't.

My theoretical position taken throughout this thesis, therefore, had to enable me to present possibilities for an enabling narrative of sociality and friendship for persons with autism that: 1) deconstructs the binary of autistic and PNT sociality, and, therefore, advances a challenge to this dominant discourse on sociality and friendship and; 2) argues for a range of sociality and friendship possibilities across being human. To do so, I needed to describe in my research the meaning of sociality and friendship of persons with autism from their perspective. I, therefore, rejected the medical model of disability ideology understanding of autism that is based on the PNT perspective as the ideal state of being human (Mallett and Runswick-Cole, 2014), and positions persons with autism in comparison as being deficient and impaired (APA, 2013b).

Instead, my theoretical position has been shaped by alternative understandings of autism that, for me, argue for a range of sociality and friendship opportunities across being human. These alternative understandings include: 1) the social model of disability (Oliver, 1983); 2) the theory of disadvantage that acknowledges the frequently disadvantaged outcome of persons with autism in a PNT dominated society (Beardon 2017); 3) the neurodiversity movement that recognises the autism neurotype as a natural variation of the human (Singer, 1999); and 4) the principles of CAS that seeks to advance a challenge to the dominant medical model of disability understanding of autism (Davidson and Orsini, 2010).

I then turned my attention to interpreting through the lens of my theoretical position the key concepts of relevance to my focus of enquiry. I concluded that the cross-neurological ToM concept (Beardon, 2017) and double empathy hypothesis (Milton, 2014) present possibilities for an enabling narrative of sociality and friendship for persons with autism. In addition, the meaning of sociality and friendship described by persons with autism aligned with my theoretical position. I examined the concept of shared behaviours (Beardon, 2017), and concluded that whilst more likely to be observed in persons with

autism the same behaviours can also be found to a lesser extent in the PNT. Finally, I explored the concepts of normalcy and ableism. For me, these concepts represent the disabling social barriers that persons with autism encounter in the meaning they describe of sociality and friendship. From my perspective, these social barriers positioned the sociality of persons with autism as lesser, other, and as lacking social skills in comparison to PNT sociality and prevented persons with autism from making friends and maintaining friendships. Having summarised my thesis, I now present my reflections on my research journey.

6.2 Reflecting on my research journey

In undertaking this qualitative research project, I aimed to describe the complex and varied meaning of the sociality and friendship experiences of persons with autism from their perspective. I needed, therefore, to align my philosophical and methodological framework with my theoretical position. In doing so, my researcher positionality was of critical importance. My researcher positionality has been influenced by several factors that included: 1) the academic research I have completed; 2) my lived experience as the mother and parent-researcher and 3) being a researcher without a disability researching a disability. My researcher positionality, therefore, presented me with academic tensions and barriers in how to position my research in a philosophical framework that aligned with my theoretical position.

To account for these academic tensions and barriers, I was required throughout my research to recognise and reflect on my bias, whilst acknowledging the value of my emotional connection to my focus of enquiry. I also concede there is ambiguity in the efficacy of a non-disabled researcher such as myself conducting disability research and that this issue may, therefore, be the subject of continuing academic debate. However, whilst acknowledging these issues as limitations of my study, I wanted to understand more about how persons with autism experience these phenomena from their perspective and this was the purpose of my research.

My qualitative enquiry reflected my commitment to emancipatory disability research that with its foundations in the disability movement supported my theoretical position, reflected my researcher positionality, and allowed me to answer my research questions. To avoid placing participatory demands on persons with autism, I used existing on-and off-line data sources that I believe have allowed me to gain insight into the meaning of sociality and friendship of the sources from their perspective. Whilst I acknowledged emancipatory disability research is complex and difficult to achieve in practice, I argued that my work can emancipate by presenting possibilities for an enabling narrative of sociality and friendship for persons with autism. I claim, therefore, that the design and conduct of my research have resulted in findings that are trustworthy (Lincoln and Guba, 1985).

Having summarised my thesis and reflected on my research journey, I now conclude by presenting the contribution to knowledge that I am making and the changes in professional practice that I have recommended.

6.3 Contribution to knowledge and recommendations for practice

In answering my research questions, I make three contributions to knowledge that lead to five recommendations for changes in practice. My contributions to knowledge are:

Contribution one: the meaning described of sociality and friendship of persons with autism. The sources desired to socialise, make friends, and maintain friendships and different sources defined friendship in various ways. The persons with autism in my study understood how to make friends and had had successful friendship experiences. These positive experiences of friendship had enabled sources to make an emotional connection with a person, object, or animal and had made them happy. Some sources also aspired to socialise and make friends in the future.

Some sources claimed to know other persons with autism described the same meaning from sociality and friendship and that they too wanted to socialise,

make friends, and maintain friendships. Although sources had had positive sociality and friendship experiences, they described many more negative ones. Sources had frequently failed to socialise, make friends, and maintain friendships and this resulted in negative emotional states.

In wanting to socialise, make friends, and maintain friendships, the sources described from their perspective a meaning of sociality that was distinct from that of PNT persons that I labelled as autistic sociality. The sources regarded PNT sociality as the only trusted pathway to making friends and maintaining friendships that was correct, obtainable, and preferred. For the sources, this recast their meaning of sociality and friendship as inferior, other, and lesser.

Contribution two: the social barriers encountered by persons with autism in experiencing sociality and friendship. The sources encountered the disabling social barriers of normalcy and ableism. Despite their successes in making friends and maintaining friendships, the sources distrusted their sociality. The PNT meaning of sociality had been internalised by the sources as distinct from their autistic sociality, the correct, obtainable, trusted, and only way of being. The sources didn't appear to have a conscious realisation of the prejudicial ideas of society, and these were naturally embedded in them. For the sources, describing the PNT meaning of sociality and friendship and its mastery was paramount. This meaning wasn't questioned, communicated, or was required to be formally acknowledged by the sources.

Contribution three: overcoming the social barriers encountered by persons with autism in experiencing sociality and friendship. The task of overcoming these social barriers was regarded by the sources as being their responsibility alone, and could only be achieved by developing and mastering PNT social skills and personal qualities. Sources didn't expect the PNT to gain an understanding of their sociality or to change or deviate from their meaning or position of ontological security.

I argue that this binary of autistic and PNT sociality resulted from encountering the disabling social barriers of normalcy and ableism. For me, overcoming

these social barriers requires broader constructions of sociality and friendship that include the meaning described by persons with autism, and in particular the recognition of behaviours that are shared by both persons with autism and the PNT. Recognising this overlap of behaviours I also suggest will contribute to resolving the conundrum that despite the sociality of persons with autism, the positive experience of friendship that they desire and enjoy is difficult for them to achieve. The recommendations that I have made to inform professional practice, both my own and that of other professionals, may facilitate this process and, therefore, contribute to overcoming these social barriers. My recommendations for professional practice I summarise as:

Recommendation one: parental practice. That parents communicate to their children alternative possibilities for enabling narratives of sociality and friendship, to facilitate their socialising, making friends, and maintaining friendships. I intend that my own parenting practice is also framed this way.

Recommendation two: mental health professional practice. That all mental health workers receive awareness training on the positive influence of socialising, making friends, and maintaining friendships on the mental health of persons with autism.

Recommendation three: education professional practice. That all education professionals receive awareness training for children with autism on: 1) the importance of social engagement and friendship to facilitate better outcomes; 2) the range of possibilities for sociality and friendships; and 3) the benefits of peer networks with PNT children.

Recommendation four: education professional practice. That the importance of socialising and friendship to children with autism (including the many forms this may take) be communicated to PNT children.

Recommendation five: academic writing practice. That (through my own dissemination) academics present possibilities for an enabling narrative of sociality and friendship of persons with autism.

These recommendations I posit may affect change and, therefore, achieve broader constructions of sociality and friendship for persons with autism: 1) by deconstructing the binary of autistic and PNT sociality, and, therefore, advancing a challenge to the dominant discourse on sociality and friendship for persons with autism; and, 2) arguing for a range of sociality and friendship possibilities across being human. There is I conclude **one sociality** that represents a range of possibilities across being human that enables friends to be made and friendships to be maintained by both persons with autism and the PNT.

Finally, I would like to conclude by reflecting on the meaning my son describes of his lived experience of sociality and friendship. His wish to socialise but finding the positive experience of friendship difficult to achieve isn't, for me, a conundrum but a product of the PNT society that my son inhabits that results in his disadvantaged outcome. For my son developing an understanding of PNT sociality has been a necessity to enable him to make friends and maintain friendships. In the future, I hope the realisation of broader constructions of sociality and friendship will enable my son to trust his sociality, and fulfil his desire of making friends and maintaining friendships. There is clearly more work to be done to dispel the dis/human myth that persons with autism aren't social beings.

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Appendix One: Data sources

No.	Source	Title, URL and date first accessed ⁷¹	Background Information
1	Victoria Hammond (YouTube, 2013)	Asperger Syndrome – how to make and keep friends. Published 22/08/13. https://www.youtube.com/watch?v=cGcUcarzXGE 2 nd and 3 rd October 2014.	Length twelve minutes and one second. Victoria is twenty-four years old and has her own YouTube channel. She was diagnosed at six years old with AS. Victoria started her YouTube channel to promote her aspie gifts of music and make up.
2	Arman Kody (YouTube, 2012a)	RE: Autism/Asperger's friendship. Published 03/04/12. http://youtu.be/t96-13IY9JM 2 nd and 3 rd October 2014.	Length five minutes and seventeen seconds. Arman describes himself as an autistic adult. He has his own autism website Empowerautismnow.com a group that aims to positively shift the perception of autism on a worldwide level.

⁷¹ The date accessed refers to the collection and transcription date that may have been completed over more than one day.

No.	Source	Title, URL and date first accessed	Background Information
3	Alex Plank (YouTube, 2014a)	How can teens with autism make friends? http://youtu.be/ZH7Hemha1y0 2 nd and 3 rd October 2014.	Autism Live. Published 16 th January 2014. Length two minutes and fifty seconds. Alex is an adult and was diagnosed with AS at nine years old. He has his own website Wrongplanet.net for. "individuals and parents and professionals of those) with autism, AS and other neurological differences".
4	Nathan Selove (YouTube, 2014b)	Autism actually speaking: making friends. http://youtu.be/jqJ8qwd2ShI 2 nd and 3 rd October 2014.	Oakcroft films. Published 17 th June 2014. Length five minutes and ten seconds. Nathan in an adult on the autism spectrum. He runs Oakcroft films with two other people that publish a series of video blogs called, "autism actually speaking".
5	Kerry Flynn (YouTube, 2014c)	Friendship and Aspergers Syndrome. http://youtu.be/C1x3zWNO05c 2 nd and 3 rd October 2014.	Published 14 th April 2014. Length three minutes and three seconds. An adult man who was diagnosed with AS at eight years old. Kerry has a website called, "a journey to acceptance" and is a motivational speaker on the autism spectrum.

No.	Source	Title, URL and date first accessed	Background Information
6	James (Healthtalk, 2010a)	Autism and friends. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 3 rd October 2014.	Last updated November 2010. Video title, “ In his last year at school James found that he had made friends without realising at the time”. Length two minutes and fifty seconds. James was diagnosed with AS when he was twelve years old. He is studying at university for a degree in psychology.
7	Richard (Healthtalk, 2014a)	Life on the autism spectrum ⁷² . http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-feeling-different-wanting-fit 3 rd October 2014.	Research copyright 2014. Video title, “Richard had a solitary childhood”. Length one minute. Richard is fifty-eight years old and was diagnosed at age fifty-one. Richard was diagnosed with AS seven years ago after being referred to a specialist diagnostic centre. Richard, a computer programmer, has been married for over thirty years and has a large family.

⁷² Richard’s interview was only available as a transcript. Time length is an estimate by reading.

No.	Source	Title, URL and date first accessed	Background Information
8	Richard (Healthtalk, 2014b)	Life on the autism spectrum. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/richard-interview-12b 3 rd October 2014.	Research copyright 2014. Video title, “Richard has various friends that he plays games and watches television with”. Length fifty eight seconds. Richard is twenty-two years old and was diagnosed with autism at two years old. He lives in independent supported living accommodation and is unemployed.
9	Mary⁷³ (Healthtalk, 2010b)	Autism and friends. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 3 rd October 2014.	Last updated November 2010. Video title, “Mary gets on better with people older or younger than her. She thinks this is because she is less interested in fashion and the music that people her age like”. Length one minute and twenty-six seconds. After researching various conditions on the Internet, Mary was diagnosed with AS aged twenty-one. She also has Obsessive Compulsive Disorder and anxiety. Mary is single and unemployed has recently graduated from university and does voluntary work.

⁷³ Two interviews were transcribed for several sources from the Healthtalk.org website. These were for Richard interviews 2014a and 2014e, Mary interviews 2010b and 2010i, Sam 2014c and 2014f, Ian 2010c and 2010g, Catherine 2014d and 2014g and Simon 2010i and 2010k.

No.	Source	Title, URL and date first accessed	Background Information
10	Sam (Healthtalk, 2014c)	Life on the autism spectrum. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/sam-interview-17b 6 th January 2015.	Research copyright 2014. Video title, "Sam recalls an, 'emotional distance' between himself and other children". Length one minute and fourteen seconds. Sam is an adult male who was diagnosed with AS two years ago. He is studying for a PhD and lives by himself.
11	Ian (Healthtalk, 2010c)	Autism and friends. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 6 th January 2015.	Last updated November 2010. Video title, "Ian finds it easier to make friends with autistic people as they think the same". Length one minute and seven seconds. Ian is twenty-two years old and was diagnosed with autism at eight years old. He is currently doing a vocational table-waiting course and is interested in palaeontology and film-making. He is single and a student.

No.	Source	Title, URL and date first accessed	Background Information
12	Mark (Healthtalk, 2010d)	Autism and friends ⁷⁴ . http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 6 th January 2015.	Last updated November 2010. Video title, “Mark says he tends to approach people with a ‘level of emotional detachment’”. Length one minute. Mark is twenty-seven years old and was diagnosed with AS when he was twenty-six years old. He is returning to university to study economics and accounting.
13	Debumaiya (YouTube, 2010)	Autism and friendships. https://www.youtube.com/watch?v=8dbJkZ0tY1I 6 th January 2015.	Published 3 rd April 2010. Length three minutes and forty three seconds. Debumaiya is an adult male with a diagnosis of autism. He uploads, “a variety of videos for anyone to enjoy”.
14	Andrew Bushard (YouTube, 2011a)	Asperger’s syndrome. Making friends in a big city. https://www.youtube.com/watch?v=A_gW4WY5nil 6 th January 2015.	Published 9 th March 2011. Length three minutes. Andrew is an adult male with a diagnosis of AS. He has written books on his lived experiences.

⁷⁴ Mark’s interview was only available as a transcript. Time length is an estimate by reading.

No.	Source	Title, URL and date first accessed	Background Information
15a)	Tony⁷⁵ (YouTube 2012b)	BBC my autism and me. https://www.youtube.com/watch?v=ejpWWP1HNGQ	Published 30 th January 2012. Length twenty four seconds. Tony speaks at six minutes and forty-seven seconds. Ben speaks at nine minutes and twenty-six seconds. Length two minutes and forty seconds. Both children have a diagnosis of autism.
15b)	Ben (YouTube 2012b)	6 th January 2015.	
16	Alex (Healthtalk 2010e)	Autism and friends. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 2 nd September 2015.	Last updated November 2010. Video title, "Alex has online friends who help her by checking that she has eaten or locked her doors". Length one minutes and forty-five seconds. Alex is a twenty eight year old female. Alex was diagnosed with classic autism aged three years old. She lives independently in an adapted house, with some care assistance. A few years ago she was injured in a road accident and, as a result, now has epilepsy. Alex is unemployed and single.

⁷⁵ Note for Tony and Ben only the part of the interview they appeared in was transcribed.

No.	Source	Title, URL and date first accessed	Background Information
17	Oliver and Susie (Healthtalk, 2010f)	Autism and friends. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 2 nd September 2015.	Last updated November 2010. Video title, "Susie thinks Oliver has a lot of friends but he finds defining friends difficult". Length two minutes and forty-one seconds. Oliver is a twenty seven year old male. Oliver was diagnosed with AS two years ago. His mother and younger brother had also been diagnosed with AS previously. Oliver describes his family as easy going and not concerned about what other people think about them. Oliver is a student and lives with his partner Suzie.
18	Catherine (Healthtalk, 2014d)	Autism feeling different and wanting to fit in. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-feeling-different-wanting-fit 2 nd September 2015.	Research copyright 2014. Video title, "When she was first at school, Catherine had no friends apart from her cousin". Length fifty five seconds. Catherine, twenty-seven, was diagnosed with AS when she was twenty-three. She works part time as a volunteer gardener.

No.	Source	Title, URL and date first accessed	Background Information
19	Sillygayboy (YouTube, 2011b)	Aspergers loosing friends. https://www.youtube.com/watch?v=JuuKxEavlGo 2 nd September 2015.	Published 7 th February 2011. Length four minutes and eleven seconds.
20	EvieMay (YouTube, 2011c)	Value of having friends – just a girl with Aspergers. https://www.youtube.com/watch?v=WG-wgkJD1b8 2 nd September 2015.	Published 11 th March 2012. Length four minutes and fifteen seconds. Evie May is a young teenage girl and was diagnosed with AS when she was nine years old. YouTube is a way for her to express herself and to reach out to other kids.
21	Erinclem (YouTube, 2012c)	On Asperger's and friendship. https://www.youtube.com/watch?v=-H0zLA5DTIQ 2 nd September 2015.	Published 7 th January 2012. Length five minutes and twenty-three seconds. Erinclem is a twenty-five year old girl with AS and lives in North America.

No.	Source	Title, URL and date first accessed	Background Information
22	Ian (Healthtalk, 2010g)	<p>Making friends, social life and autism.</p> <p>http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/making-friends-social-life-autism</p> <p>3rd September 2015.</p>	<p>Last updated November 2010. Video title, "Ian doesn't let anything bother him now". Length thirty seven seconds. Ian is twenty-two and was diagnosed with autism with he was eight years old. He is currently doing a vocational waiting at table course and is interested in palaeontology and film-making. He is single and a student.</p>
23	Daniel (Healthtalk, 2010h)	<p>Making friends, social life and autism.</p> <p>http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/making-friends-social-life-autism</p> <p>3rd September 2015.</p>	<p>Last updated November 2010. Video title, "Margaret describes how Daniel has learnt some responses and he says things because he thinks it's the right thing to say". Length one minute and five seconds. Daniel was diagnosed with AS when he was eleven years old. He does voluntary work one day a week and Margaret runs a support group for people with AS.</p>

No.	Source	Title, URL and date first accessed	Background Information
24	Richard (Healthtalk, 2014e)	<p>Making friends, social life and autism. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/making-friends-social-life-autism 3rd September 2015.</p>	<p>Research copyright 2014. Text version only. Video title, “Richard describes, while has learnt some body language over the past two years, ‘I don’t communicate own emotions because my emotions don’t usually communicate themselves to my mind’”. Length estimated from reading. Two minutes. Richard is fifty-eight years old and was diagnosed at age fifty one. Richard was diagnosed with AS seven years ago after being referred to a specialist diagnostic centre. Richard, a computer programmer, has been married for over thirty years and has a large family.</p>

No.	Source	Title, URL and date first accessed	Background Information
25	Simon (Healthtalk, 2010i)	<p>Making friends, social life and autism. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/making-friends-social-life-autism 3rd September 2015.</p>	<p>Last updated November 2010. Video title, “Simon has studied the art of conversation. He is learning ways of managing his emotions more effectively to avoid self harming”. Length one minute and twenty nine seconds. Simon is twenty-two years old and was diagnosed when he was five years old. He has developed his own strategies to cope during social situations. Simon is interested in animals and aims to find employment in this area. Simon does talks on autism to help people to understand. Simon is qualified in animal management and does voluntary work.</p>

No.	Source	Title, URL and date first accessed	Background Information
26	Russell (Healthtalk, 2010j)	<p>Making friends, social life and autism. http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/making-friends-social-life-autism 3rd September 2015.</p>	<p>Last updated November 2010. Video title, “Russell has become more cautious as he has grown up and feels more wary of possible dangerous situations”. Length one minute and thirty seven seconds. Russell is twenty-one years old and was diagnosed with AS when he was twelve years old. His awareness of potential difficulties is increasing as he grows older and more aware. Russell describes himself as being prone to outbursts and is taking anti-depressants. He has an accountancy degree and is seeking an apprenticeship in business administration.</p>
27	Sam (Healthtalk, 2014f)	<p>Autism and friends http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 4th September 2015</p>	<p>Research copyright 2014. Video title, “Sam finds a lot of people ‘banal’ but found having a friend at university made a ‘massive difference’ to him”. Length forty-four seconds. Sam aged twenty-four years was diagnosed with AS two years ago. He is studying for a PhD and lives by himself.</p>

No.	Source	Title, URL and date first accessed	Background Information
28	Simon (Healthtalk, 2010k)	Autism and friends http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 4 th September 2015	Last updated November 2010. Video title, “It took Simon a while to learn what a friend was and explains how he finds it hard to trust people”. Length two minutes and thirty five seconds. Simon, aged twenty-two was diagnosed with autism when he was five years old. He has developed his own strategies to cope during social situations. Simon is interested in animals and aims to find employment in this area. Simon does talks on autism to help people to understand. Simon is qualified in animal management and does voluntary work.
29	Catherine (Healthtalk, 2014g)	Autism and friends http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 4 th September 2015	Research copyright 2014. Video title, “Catherine has learnt how to ‘sit about with people’ from Neil and is amazed she can now do that”. Length one minute and fifteen seconds. Catherine, twenty-seven, was diagnosed with AS when she was twenty-three. She works part time as a volunteer gardener.

No.	Source	Title, URL and date first accessed	Background Information
30	Mary (Healthtalk, 2010l)	Autism and friends http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends 4 th September 2015	Last updated November 2010. Video title, “As a child, Mary was very clingy and obsessive about friendships”. Length of interview two minutes and forty-three seconds. After researching various conditions on the Internet, Mary was diagnosed with AS aged twenty-one. She also has OCD and experiences anxieties. Mary is single and unemployed. She has recently graduated from university and does voluntary work.
31	Stephen (Healthtalk, 2010m)	Autism Making friends, social life and autism http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/making-friends-social-life-autism 4 th September 2015	Last updated November 2010. Video title, “Steven describes how, although he was found strategies to help him fit in, life still feels like having a job interview fifty times a day”. Length of interview three minutes and eleven seconds. Steve and his son have been diagnosed with AS. Steve is studying for a degree in autism using distance learning and has heightened sensory sensitivities and some OCD traits. Steve and his wife have one son, aged nine.

No.	Source	Reference	Background information
1	Steve Jarvis (Jarvis, 2008)	Chapter 2: Developing a better social understanding. Asperger syndrome and social relationships – adults speak out about Asperger Syndrome series. 2008. Jessica Kingsley Publishers. Accessed Thursday 19 th and Friday 20 th November 2015.	Steve Jarvis lives alone in Hertfordshire and has lived on his own all his adult life. He works as a learning consultant and has been in full-time employment all his life, but has never had any success with relationships. He was diagnosed with AS when he was forty-five years old.
2	Hazel D.L. Pottage (Pottage, 2008)	Chapter 3: The difficulty of social contact and the impact on my mental health. Asperger syndrome and social relationships – adults speak out about Asperger Syndrome series. 2008. Jessica Kingsley Publishers. Accessed 23 rd November 2015.	Hazel D.L. Pottage, or Haze for short, has always had problems relating to others and in 1976 had a severe mental breakdown and was in an institution for three years. Already diagnosed with dyslexia and dyspraxia, she was officially diagnosed with AS in 2004. Her hope for the future is that, as AS becomes more recognised, life will be much easier for children growing up with the condition than it was for her, and that adults will be more accepting and tolerant of each other.

No.	Source	Reference	Background information
3	Wendy Lawson (Lawson, 2001)	Understanding and working with the spectrum of autism. 2001. Jessica Kingsley Publishers. Accessed 23 rd November 2015.	Wendy Lawson was diagnosed in adulthood with AS. A psychologist, qualified counsellor and social worker she has operated her own private practice for many years. The mother of four children, Wendy has been married, separated and divorced, Wendy's youngest son is also on the autism spectrum.
4	Rachael Lee Harris (Harris, 2015)	My autistic awakenings. 2015. Roman and Littlefield. Accessed 24 th November 2015.	Rachael Less Harris is a registered psychotherapist specialising in AS and high functioning autism providing a unique contribution to the field of autism spectrum conditions (ASC) therapy and research from her perspective as a woman who has been diagnosed with AS.

No.	Source	Reference	Background information
5	Jessica Pears (Pears, 2004)	Asparagus Dreams. 2004. Jessica Kingsley Publishers. Accessed 26 th November 2015.	Jessica was diagnosed with AS at twelve years old, and was then educated at a residential school for young people with autism. She is currently a voluntary researcher at the Autism Research Unit (University of Sunderland).
6	Rudy Simone (Simone, 2010)	Aspergirls: Empowering girls with Asperger Syndrome. 2010. Jessica Kingsley Publishers. Accessed 2 nd December 2015.	In 2011 Rudy Simone, now fifty-one years old, self-diagnosed with AS. Rudy promotes a “cultural exchange” between the non-autistic and autistic communities. She also promotes self-advocacy and management of the challenges inherent in AS.
7	Giles Harvey (Harvey, 2008)	Chapter Four: Relationships for people with Asperger Syndrome: How to help people understand. Asperger syndrome and social relationships – adults speak out about Asperger Syndrome series. 2008. Jessica Kingsley Publishers. Accessed 3 rd December 2015.	Giles Harvey was diagnosed with AS in 1997 at the age of twenty-two. He has had several jobs including working for a large charity in North West England that supports people with a diagnosis of AS. It was from this post that Giles developed a further interest in and knowledge of AS.

No.	Source	Reference	Background information
8	Alexandra Brown (Brown, 2008)	Chapter Six: Social Relationships and social inclinations. Asperger syndrome and social relationships – adults speak out about Asperger Syndrome series. 2008. Jessica Kingsley Publishers. Accessed 8 th December 2015.	Alexandra Brown prefers to be known as Alex. She lives with her partner and teenaged daughter in North Yorkshire. She has worked full-time for the past seven years within library services. She loves books but isn't always so fond of the people! Alex received her diagnosis of AS in 2007 at the age of thirty-eight. She enjoys writing, mainly for her friends, and uses writing to analyse her thoughts and make sense of the world around her.
9	Patrick McCabe (McCabe, 2003)	Living and loving with Asperger Syndrome. Family viewpoints. 2003. Jessica Kingsley Publishers. Accessed 8 th December 2015.	Patrick McCabe has had AS for forty-four years. He has a varied background in the field of writing and has created manuals for his work with the Denver Rescue Mission, currently he writes articles for organisational newsletters. While in university he wrote a seven chapter thesis. Patrick has taken college level composition courses as well as attending a nationally recognised writers seminar.

No.	Source	Reference	Background information
10	Haley Moss (Moss, 2014)	<p>A freshman survival guide for college students with autism spectrum disorders. 2014. Jessica Kingsley Publishers.</p> <p>Accessed 10th December 2015.</p>	<p>Hayley Moss is a contemporary American artist and author. Diagnosed at age three with High-Functioning Autism, she has been described as an inspirational author, artist and advocate for children with disabilities. She works with many charities and organisations.</p>

Appendix Two: Examples of thematic analysis

2.1 Phase One - Familiarising yourself with your data

Mary (Healthtalk, 2010b)⁷⁶

<http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/autism-friends>

You said you think it's easier to make friends or be with people who are older or younger. It's more difficult with your peer group? Yes. Why do you think that is?

I think, maybe because peer group are kind of more focussed on... it's very difficult to say really, but I think, how can I put it? It's like people who are older than me are, they're kind of more, I find it easier to relate to them, maybe because I'm very old and young at the same time [laughs]. I mean I do lots of, I don't really do things that people my own age group really do. I'm not really that interested in fashion or kind of I don't know, just like what's fashionable, what's in the, what's the latest, you know, things like music. I mean I like music, but I tend to choose more my own type of music. So, I'm not really that interested in people my own age, and what they're interested in. So that's when I say, like I feel old in that level. People who are older than me, you know, are just kind of... just maybe they don't talk so much about, maybe it's more like small talk, maybe people my age are more small talk based. I don't know, more gossiping which I don't get. People younger than me, I can relate to more, because they're, because they're, on the hand I think I'm quite immature in other respects as well. So people younger than me I can relate to as well in that sense, their sense of humour and stuff like that.

Joanna Baker-Rogers 8/12/16 12:44
Comment: Qualities/reflective

Joanna Baker-Rogers 8/12/16 12:44
Comment: Activities/opportunities to make friends.

Joanna Baker-Rogers 8/12/16 12:44
Comment: Activities/lack of shared interests inhibits making friends own age.

Joanna Baker-Rogers 8/12/16 12:44
Comment: Activities/lack of shared interest inhibits making friends own age.

Joanna Baker-Rogers 8/12/16 12:44
Comment: Qualities

Joanna Baker-Rogers 8/12/16 12:44
Comment: Qualities

Joanna Baker-Rogers 8/12/16 12:44
Comment: Dialogue conceptualised as friendship. Appropriate dialogue

Joanna Baker-Rogers 8/12/16 12:44
Comment: Lack of appropriate dialogue

Joanna Baker-Rogers 8/12/16 12:44
Comment: Self criticism. Shared interests opportunity to make friends.

Joanna Baker-Rogers 8/12/16 12:44
Comment: Shared interests opportunity to make friends.

⁷⁶ To enable comments to be shown the text is presented as a screenshot. Formatting this appendix updated the date that the comments were made. The original dates, when I familiarised myself with the data, were the 8th and 9th January 2015.

2.2 Phase Two – Generating initial codes

Arman Khodaei YouTube 2012a (1 of 3)	
Data extract	Coded for
Do I have friends? Does friendship come easy for me?	Interested in friendship
I have a website and blog which you can visit on my website empowerautism.com.	1. Supportive 2. Virtual space
For me, I have many acquaintances but allowing myself to get close to others is a challenge. I think for many people on the autism spectrum and with Asperger's Syndrome, making friends is a challenge.	3. Acquaintances as friends 4. Difficult to make friends 5. Assumes persons with AS find friendship difficult
I do have one close friend that I stay in contact with even though she moved away to a faraway state.	1. Has a friend 2. Distance not a barrier to friendship
You know for me I have I would say one good friend at this moment I have many friends but you know none of them are really too close friends.	1. Positive experience 2. Has a friend 3. Different degrees of friendship
I have one good friend who lives in Wisconsin. We stay in contact.	5 Has a friend 6 Distance not a barrier to friendship
I consider all the people that come to my groups my autism groups that I run to be friends. And we have liked 50 group members so but you know I don't really see them beyond you know the medians or activities that we do.	1. Large group 2. Limitations of friendship group

Arman Khodaei YouTube 2012a (2 of 3)	
Data extract	Coded for
So for me it's a challenge to you know I want to do more as a person. Its very hard for me to really you know get close to other people for various reasons. You know one of the big reasons is that I am really self absorbed honestly. I mean I am really a selfish person at times you know for better or for worse. I really am pretty selfish and and unfortunately you know that means for me I am not the best at listening to people.	<ol style="list-style-type: none"> 1. Anticipates difficulties in making friends 2. Not desirable friendship qualities in himself 3. Own fault
I try to listen and then you know sometimes I want to talk about my own self you know. I need to get better at that. I'm working on it you know I'm recognising this you know sometimes I feel like I'm a good friend and sometimes I'm not that certain in that regard.	<ol style="list-style-type: none"> 1. Not desirable friendship qualities in himself 2. Own fault 3. Self improvement
I just become so absorbed with you know writing and my book and everything else and you know I don't really feel lonely at times. I guess having people meeting some people I don't necessarily really feel lonely. There is a lot of alone time in my every day to day life.	<ol style="list-style-type: none"> 1. Doesn't have the need for friends all the time 2. Doesn't feel lonely
I still go social dancing and I would say a couple of people there I have met there are my friends at the social dancing that I do.	<ol style="list-style-type: none"> 1. Shared physical space 2. Activity as opportunity 3. Has friends

Arman Khodaei YouTube 2012a (3 of 3)	
Data extract	Coded for
But I know its hard for me to allow myself to you know become friends with people to really open up with other people.	1. Anticipates difficulties due to lacking desirable friendship qualities
Friendships don't come easily to me.	2 Negative experience 3 Hard to make friends
I can be with a large group or a small group of people.	Small or large groups
I'm in charge and there's usually a direction that everyone's going on.	Control and influence
But I guess overall I do prefer hanging out one on one with people. I'm not used to hanging out with you know two people at a time. I usually am a very one on one person.	Prefers one on one
I consider myself to have many friends but I consider myself to be selfish in my relationships unfortunately.	1. Has friends 2. Positive experience 3. Not desirable friendship qualities in himself 4. Regret
I'm trying to help other people gain better social skills and at the same time I have to work on my own social skills and so I'm working on it I'm trying to become the best person I can be.	1. Social skills training 2. Supportive 3. Greatness

2.3 Phase Three – Searching for themes

Experience	Ableism
<p>Negative experience</p> <p>No friends</p> <p>Transient friends</p> <p>Not making friends at new school</p> <p>Friends not interested in him</p> <p>Not having a negative experience was positive</p> <p>Lack of acceptance</p> <p>Tried hard but failed to make a friend</p> <p>Difficult to make friends</p> <p>Positive experience</p> <p>Has friends</p> <p>Has maintained friendships</p> <p>Had friends</p> <p>Had great friends</p> <p>Has had positive and negative experiences</p> <p>Difficult to make friends compared to neurotypicals</p> <p>Difficult to make friends due to AS</p> <p>Misinterpreted approaches</p> <p>Negative experience with neurotypicals</p> <p>Difficult to make friends with neurotypicals</p> <p>Difficult to converse with neurotypicals</p> <p>Adapting to neurotypicals difficult</p> <p>Lack of activity/shared experience resulted in no friends</p> <p>Older people as friends</p> <p>Younger people as friends</p> <p>Different types of friendship length</p> <p>Distance not a barrier to friendship</p> <p>Different degrees of friendship</p> <p>Strong aspirations for a particular friend</p>	<p>Greatness</p> <p>Self improvement</p> <p>Social skills training</p> <p>Has improved social skills</p>

2.4 Phase Four – Reviewing themes

Success and failure
Negative experience
No friends
Difficult to make friends
Difficult to make friends compared to neurotypicals
Difficult to make friends due to AS
Difficult to make friends with neurotypicals
Adapting to neurotypicals difficult
Conversation difficult
Unsuccessful strategy
Not making friends at new school
Friends not interested in him
No desirable qualities in people own age
Lack of shared interests inhibits making friends own age
Lack of activity/shared experience resulted in no friends
Anticipates difficulties due to moving
Anticipates difficulties due to lacking desirable friendship qualities
Anticipates difficulties for friends left behind
Strategy to avoid negative experience
Not having a negative experience was a positive
Positive experience
Has friends
Had friends
Had great friends
Has maintained friendships
Successful strategy
Using a successful strategy to make new friends in the future
Good conversation with Aspies
Believes persons with AS can make friends
Older people as friends
Younger people as friends

Anticipates success in making friends
 Successful at making friends
 Unanticipated success
 Surprised at success
 Anticipates other people will want to be friends with her
 Won competition
 Has had positive and negative experiences
 Not making friends at new school
 Friends not interested in him
 Lack of acceptance
 Tried hard but failed to make a friend
 Negative experience with neurotypicals
 Different degrees of friendship
 Social skills training
 Body language
 Has improved social skills
 Upset a friend
 Lack of emotional connection
 Peers not as friends
 Lack of appropriate conversation
 Surprised other people by own success
 Surprised other people that in that someone with AS could make friends
 Surprised at acceptance by neurotypicals
 Assumes persons with AS find friendship difficult
 Anticipates difficulties in making friends
 Anticipates difficulties due to AS
 Anticipates difficulties due to lacking desirable friendship qualities
 Own fault
 Not desirable friendship qualities in himself
 Aspie website to make aspie friends
 Believes persons with AS can make friends
 Greatness
 Self improvement
 Social skills training
 Has improved social skills

Appendix Three: Example of data saturation table

Saturation table completed at the end of the first phase of data collection (October 2014)⁷⁷.

Topic	Source								
	1 ⁷⁸	2	3	4	5	6	7	8	9
Interested in friendship	✓	✓	✓	✓	✓	✓	✓	✓	✓
Wants friends	✓	✓	✓	✓	✓	✓		✓	✓
No friends							✓		
Has or had friends	✓	✓		✓	✓	✓		✓	✓
Difficulties in making friends	✓	✓	✓	✓	✓	✓	✓		✓
Strategies to make friends	✓	✓	✓	✓	✓	✓			✓
Success in making friends	✓	✓	✓	✓	✓	✓		✓	✓
Assumes persons with autism want friends	✓		✓	✓	✓				

⁷⁷ The format of the saturation table is as based on the guidance in Brod, Tesler, and Christensen, 2009.

⁷⁸ The source numbers correspond with those cited in Appendix One.

Topic	Source								
	1	2	3	4	5	6	7	8	9
Assumes persons with autism find it difficult to make friends	√	√	√	√	√				
Supportive of persons with autism in making friends	√	√	√	√		√			
Social skills training	√	√	√	√		√			
Body language	√		√						
Negative experience	√			√			√		
Positive experience	√	√	√	√	√		√	√	
Negative emotions	√		√	√		√			
Positive emotions	√	√				√	√		

Topic	Source								
	1	2	3	4	5	6	7	8	9
Desirable qualities in people	√		√	√					√
Different numbers of persons as friends	√	√		√					
Choice in friends	√	√		√					√
Normalcy	√	√		√		√	√		√
Opportunities to socialise/make friends	√	√	√	√	√	√	√	√	√
Distance not a barrier to friendship		√							
Different degrees/types/ lengths of friendship		√			√				
Limitations of friendship groups		√							
Not desirable friendship qualities in self		√	√				√		√
Leaving friends behind difficult					√				

