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Faculty of Development and Society

Exploring the impact of a developing sexuality on adolescents with autism

by

Thomas Robert Andrews

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ABSTRACT

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Abstract - This research project sought to understand as far as possible what meanings the period of development termed as 'adolescence' meant for a small group of young men on the autism spectrum, as interpreted by the parents and staff who support them. The focus of my enquiry was an exploration of interpretations of behaviour; specifically 'sexualised behaviour' and how these interpretations might enable or disable people on the autism spectrum. In this study accessing the 'meaning of experience' for the young men within this group, as interpreted by the participants, was mediated through a supported process of reflection in which the participants challenged their initial interpretations and understandings of what the behaviours might mean to the young men. The method used was a series of individual and group interviews with the people who lived and worked with these young men, and used Ashworth's eight 'fractions' of the Lifeworld as starting off points from which to begin framing the examination and interpretation of the participant's experiences and perceptions. Throughout this research my aim and intention was to challenge some of the canons of autism in relation to sexuality and sexualised behaviour. In doing so I wanted to identify how a supported reflection might move parents and staff towards new ways of interpreting the behaviour of people on the autism spectrum, so that more appropriate and sensitive measures can be formulated in order to bring about positive sexual identity formation during adolescence.

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Section One: Context and Approach

Chapter 1 Introduction

1:1 Introduction

This thesis investigates and reports on the key aspects and processes that surround the interpretation and understanding of forms of sexuality as they relate to people on the autism spectrum. Although the topic of sexuality and autism is understudied, it should not be assumed that this population does not experience issues of sexuality (Gabriels and Bourgondien (2010:59). My goal throughout this work was not only to identify these features but also to challenge commonly held beliefs about what sexuality may represent for people with autism, and how it is typically understood for people from both the learning disabled and neuro-typical communities. Within this study the individual accounts of the participants who took part have been examined as both separate narratives and as components of a wider set of thematic links, and they are presented in narrative form using the 'fractions of the Lifeworld' (Ashworth 2003) as individual themes during the analysis of the data.

In terms of its ontological position this study resides firmly within a Critical Autism Studies (CAS) framework, a relatively new analytical framework that understands autism as a complex, relational dis/order[sic] that challenges stereotypes of what has long been regarded as "normal" human experience (Raikhel 2010). This approach explores a critical understanding of autism through three linked key themes. First: Through the construction of autistic personhood; this explores how ideas about normative childhood and adulthood impact on children and adults with autism and their families (OU 2017). Second: Neurodiversity and identity; within this framework autistic traits are positioned on a continuum with 'neurologically typical' [NT] (non autistic) behaviours, shifting the focus of discourse from disability to diversity, and in doing so nurturing and amplifying the unique strengths of people with special needs (Armstrong 2016). Third: Forms of intervention; central to this theme is the agency of people with autism and a recognition that some people will not want to engage with mainstream (NT) culture, and that autistic ways of being in the world might be incomprehensively different from the life led by those who are not autistic (Barnbaum 2009). This framework explores how our cultural contexts give rise to different kinds of 'knowledges' of autism and it examines how they are articulated, how they gain

momentum, and how they may form the basis for policy, and practice (O'Dell et al 2016). Within this framework autism is seen as wholly contextual in nature; being experienced, understood and acted upon differently across different locations, circumstances and environments. This theoretical approach argues that what may be understood as 'autism' exists in different forms which are wholly dependent on location and cultural context. Livingstone (1995); Goodley et al (2014) have argued that being human, or being recognised as human, can be seen as a process of qualification. People with autism are often the subject of inhuman treatment, which challenges us to ask - what does it mean to be human? Or what does it mean to be a human with autism? Within this approach what is of value is the notion of autistic personhood or identity positioned as being of worth, valuing the skills and abilities of people with autism and challenging a dominant deficit approach (O'Dell et al 2016).

As a researcher who works closely with young people with autism this theoretical approach has provided me with the scope to explore the central role that autistic people can play within the research process, and to explore how typical 'permitted' ways of being a human can impact on people with autism and their families. This study evolved out of my direct contact with the young people who ended up playing a pivotal role in this work and their families. From the outset I therefore set out to design a research approach that would involve both groups as much as possible. Autistic people are rarely involved in the design of any research that they themselves may be involved in, for a number of reasons; they tend to be outside of any decision making process; researchers are not 'tuned' to the wants and needs of the autistic community and there is a lack of engagement around what the priorities of people with autism are (Pellicano 2016). Originally I had wanted to learn about their experiences from the young men themselves but I could not secure ethical approval because of what was perceived as the highly sensitive nature of the topic of research. (Lee 1999:1) has argued that 'studies of 'sensitive' topics like sexual behaviour can raise questions, for example, about the kinds of research that are permissible in society, the extent to which research may encroach upon people's lives, the problems of ensuring data quality in dealing with certain kinds of topics and the ability of the power to control the research process'. It has also been suggested that investigating sensitive topics usually introduces into the research process contingencies less commonly found in other kinds of studies. Because of the threat they pose, sensitive

topics may therefore raise difficult methodological and technical problems (Lee and Renzetti 1990). So instead I got as close as possible through the facilitated interpretations of those around them. I made every attempt throughout this study to find ways to incorporate and integrate the voices and stories of all involved, in the hope that this would bring about new understandings around the ways in which human experience can be reframed through the rich and diverse lenses of autism.

1:2 Research Aims

The central aims of this study are:

- To explore the personal interpretations and individual perspectives of some of the key people in the lives of five young men on the autism spectrum, in order to examine how their involvement had impacted on these young men and the development of their sexual identity during adolescence.

- To develop an efficient participatory research methodology that would provide a way of capturing the lived experiences of this subject group, one which would provide an insight into the impact of the role played by the people around them, allowing an opportunity for their positions to be sensitively examined and this impact explored.

- To explore how meaning is attributed to the actions and behaviours of people with different ways of being and different modes of communication and to ask whether that has an enabling or disabling impact on the young men at the centre of this study and how that may frame the way in which they are supported.

- To evaluate whether sexual identity formation and self exploration during adolescence, have the same meaning for people with autism as those reported and understood by people from within the neuro-typical community.

1:3 Thesis Structure

This thesis is divided into three separate sections; Section One [Chapters 1 - 4], Section Two [Chapters 5 - 8] and Section Three [Chapter 9 – 10].

In Section One I introduce the background to the research, the key themes and the central research aims and questions that I have explored, and the way in which the study was conducted. I present a critical analysis of how the nature and experience of a disabled adolescence and a developing sexuality is currently conceptualised and responded to within the available research literature. I explain my methodology and the way in which I have analysed the data collected and explicate my motivation behind the research, focusing throughout on what it will represent for the people involved – parents, staff and subjects.

Chapter One: Introduction; in this chapter I explain the structure of the thesis; I provide the context from which this study emerged, I introduce the aims of the study and I state my research questions.

Chapter Two: Research Context; in this chapter I identify some of the key research that has informed the focus and framework for this study. I provide a brief analysis of some of the current literature available on research around the topics of disability and identity, sexuality, autism and adolescence. I explore how this literature relates to my own research focus and at the end of this chapter I restate my research questions.

Chapter Three: Methodology; in this chapter I examine the roles of the subjects and participants in this study, I present the theoretical framework that underpins the design of my research method and I provide a comprehensive examination of the design for my methodology. I explore some of the tensions, possibilities and practical challenges that I have faced when developing this methodology design. I describe how I recruited the participants and how I located the group of subjects from within the school. And I explore some of the ethical and practical issues that evolved during the implementation and design of this model.

Chapter Four: Data analysis; in this chapter I provide a detailed examination of the theoretical, conceptual and practical issues that I faced as a researcher when analysing the data that was collected. Where the previous chapter provided a detailed description of the design of the

methodology used in this project, this chapter presents a breakdown of the means by which the collected data from the one to one interviews, group meetings and research notes were analysed and the findings formulated. In this chapter I identify the coding system I designed which utilises Ashworth's 'fractions' of the Lifeworld to make sure that all aspects of experience are captured within the analysis of the data. I then go on to explore the way in which I have used the coding system, the fractions and the participants' responses to create a thematic re-evaluation of the 'meanings' that the participants have made of the subject's experiences.

In the following Chapters (five to eight) contained in Section Two, the emergent themes are reported on. The research process undertaken in this way allowed these themes to naturally emerge from the data, rather than specifically looking for the presence of certain phenomena.

In Section Two I present the findings of my data, across four separate chapters each of which deals directly with the themes and sub-themes that have emerged from the analysis of my data taken from the fractions. In these four chapters I present an examination of the core themes and sub themes extricated from the interview transcripts and research notes, exploring how they are situated within the current literature to show how the findings both inform and are informed by what is already known. This is combined with an examination of what the data appears to represent for both the subjects and the participants, and how this may relate to the experience of sexual development, identity formation and different modes of being for this group of young men, as it is interpreted by those around them.

Chapter Five: Control; in this chapter I explore the concept of Control as a central theme, exploring some of the ways in which the participants feel that the subjects have tried to exert a certain form of control over: Spaces within the home and at school, family members, other students and members of staff at school, events, experiences and the duration of situations that currently exist in their lives.

Chapter Six: Relationships; in this chapter I explore the various different ways in which the subjects are understood by the participants to have experienced discrete forms of association with those around them, with family members, staff and other students. The ways in which

the young men within this study relate to others are on occasion highly individualised and in this chapter I explore how contact, interaction and intimacy are experienced by all involved.

Chapter Seven: Communication; in this chapter I examine the outward representations and the impact of some of the different forms of communication that the subjects in this study have presented. I explore the highly idiosyncratic forms of communication that are made available by the subjects to the people who live and work with them and I present what I argue is a uniquely different form of communication that has become available within the data collected.

Chapter Eight: Identity; in this chapter I examine some of the examples available within the transcripts that describe the different ways in which the subjects are believed by the participants to have communicated their emerging identities to those around them. I explore the different forms of self validation and self identification that the subjects presented and explore the possibility of a form of interconnectivity between subjects and participants that became available within the data.

In Section Three I present a discussion of how I as a researcher have understood the findings that have emerged from this study and how I have related them back to the issues raised in the Research Context [Chapter Two], I then explore what I believe their relevance is in the wider debates that exist around this area of research. In this section I present an examination of how my findings relate back to my original research questions, and I draw the study to a conclusion providing an overall summary of what was done. I present my thoughts about what might be done differently next time, and I raise indicators for future research that may be required within this field of study.

Chapter Nine: Discussion; in this chapter, I present a discussion of my interpretations of the data I have analysed, explaining how the results and conclusions of this study are important and how they may influence our knowledge and understanding of the issues I have explored. I explain the implications of my findings and I re-examine the original aims of this study in order to consider whether these aims have been met, exploring how the results support these aims and how this fits in with existing knowledge on the topics I have explored. I comment on

the relative importance of these to my overall interpretation of the results and how they may have affected the validity of the findings.

Chapter Ten: Conclusion; in this final concluding chapter I present an overall summary of what this study set out to achieve, I provide answers to the original questions posed at the outset of this project and I discuss methodological issues that have arisen during the research. I identify both some of the limitations of this study and recommendations for possible areas of research in the future. In this final chapter I tie together, integrate, and synthesize the issues raised in Section Two and discussed in Chapter nine, while reflecting on the aims set out in the introduction. Ways in which this research has contributed to knowledge by providing additional detail, new insights and implications for the use of this information and potential generalisation of this work are discussed.

A selection of examples taken from the transcripts collected during the study, which include the extracts used throughout Section Two, along with all other relevant information directly related to this study are available in the appendices [pages 234 to 293]. These provide the reader with more information around; pen portraits of the five subjects, recruitment of participants, the types of research questions I intended to use, the way in which I was granted ethical approval for this study, and allows an opportunity to examine some of the extracts from the transcripts and research notes in more detail.

1:4 Research questions: The questions I intend to ask in this study are presented below with each provided with a link to the research aim that it is directly related to:

1. Does sexual identity formation and self exploration during adolescence, have the same meaning for people with autism as it does for those reported by people within the neuro-typical community? [Linked with Research Aims 1, 2 and 4].

2. Do the individual interpretations of the participants within this study, and the meanings they attribute to the actions and behaviours they observe have an 'enabling' or 'disabling' impact on the young men at the centre of this research? [Linked with Research Aims 1, 3 and 4].

3. Is it possible to construct a reliable research methodology that would provide a way of accessing and capturing the 'essence' of the lived experiences of people with different and divergent forms of articulacy? [Linked with Research Aims 1, 2, and 3].

1:5 Terminology

The terminology around disability is a highly contested area, not least around the naming of those who are commonly agreed to occupy the category. The current preference within most fields of disabilities studies is for 'disabled people' rather than 'people with disabilities', although even then, practice may vary (Shildrick 2012). Various words and concepts used to describe disability all have their own histories and implications for people with disabilities (Linton, 1998), and within this ongoing debate 'other supposedly more positive designations such as differently-abled, physically challenged or special needs have fallen from favour, and the use of so-called people-first language forms is now also seen as failing to encompass the significance of disability (Overboe 1999; Titchkosky 2006 as cited in Shildrick 2012:40). In this study I have used the words 'disabled' and 'disability', 'autistic' 'autism' and 'autism spectrum' interchangeably, which attests to the ongoing challenge that faces any writer working within a field of research that has these words available. People who position themselves within the autism community; autistic people, their family and friends and broader support networks – often disagree over how to describe a word such as autism, as the many discussions in print and on online forums attest (Brown, 2011 Durbin-Westby, 2009; Snow, 2006). 'Tensions surrounding the language of autism are attributable, in part, to the very different ways that autism touches people's lives; some experience it personally, others through their children and others still might only encounter autism in some aspects of their lives – at school, at work, in the community or through friends and family' (Kenny & Hattersley et al 2015:442). In this study I have used a range of different ways in which to frame autism and disability as an experience for an individual, and throughout this study descriptions of people from within this group range from: Positioned on the autism spectrum, a person or people with autism, autistic people and people on the autism spectrum. Where I have used a word such as 'disorder' I have placed [Sic] within it or next to it, in order to indicate that this is something which does not sit correctly within my own text but which is intentionally being left as it was in the original. The purpose of this guide to the terminology I have used in this study I hope

will help to provide the reader with some information on the different types of language that are used frequently when communicating about disability (Umstead 2012), it is not exhaustive but it is an indication of some of the challenges I found when attempting to position my research within this complex and ever changing field.

1:6 Summary

Throughout this study I have presented definitions of some of the key words that I have used, and where possible I have presented this in the form of a brief definition of the word/s at the start of each chapter. My intention throughout has been to use where possible only non-ableist language and to challenge both my own understanding and the current forms in which these words are utilised within research that attempts to explore alternative modes of being and different forms of expression. On some occasions in this study I have revisited certain key phrases to re-establish and re-challenge the ways in which key words are used, in this I am drawing attention to the power of words and dominant forms of language - which is something I have attempted to do continuously throughout this work.

This study has sought to understand as far as possible what 'meanings' the period of development termed as 'adolescence' may represent for a group of young men on the autism spectrum - as interpreted by a group of participants [the parents and staff who support them]. The focus of my enquiry throughout has been an exploration of interpretations of behaviour, specifically 'sexualised behaviour' and how these interpretations may act as ways to enable or disable people on the autism spectrum. In this study accessing the 'meaning of experience' for the young men at the centre of this study, as interpreted by the participants, was mediated through a supported process of reflection in which the participants worked with the researcher to challenge their initial interpretations and their grasp of what certain behaviours might mean for these young men. The method used was a series of individual and group interviews with the people who lived and worked with them, and I have used Ashworth's eight 'fractions' of the Lifeworld as starting off points from which to begin framing the examination and interpretation of the participant's experiences and perceptions. Throughout this study my aim and intention was to challenge some of the existing canons of autism in relation to sexuality and sexualised behaviour. In doing so I

wanted to identify how a process of supported reflection may assist in moving parents and staff towards new ways of interpreting behaviour for people on the autism spectrum, so that more appropriate and sensitive measures can be formulated in order to bring about positive sexual identity formation during adolescence.

Research is both a selfish and an altruistic activity, it is selfish in that one can get a real creativity and problem solving buzz from the research process. However the purpose of research is to identify and share new knowledge and to move the field of study forward in its quest for different understandings. This research study was conducted in order to gain a greater insight into the ways in which notions of sexuality and disability are understood, and to examine some of the tensions that face people on the autism spectrum as they develop and transition into adulthood. These insights are reported in the chapters that follow. However, I must also acknowledge the enjoyment I got from the research process, I not only generated knowledge about sexuality, autism and disability within this work, but I also generated personal knowledge and understanding, which has enriched my own knowledge and my practice. All of the twelve participants that took part have also reported the hugely positive effect of their involvement in this study, both on their situations at home and at school and all commented that this study had changed their perspective and offered them the opportunity to gain new understandings around the situations that they had initially reported on.

Post this study my intention is to use the findings from this study to produce new forms of practical supports for the teaching staff and families in order to assist them in developing more enabling interpretations of behaviour, that will I hope help to make the transition into adulthood easier for them and for the young people for whom they care. Because of the often sensitive nature of the involvement that was required from both parents and staff alike during this study it is important that I first acknowledge the pleasure and the pain of carrying out this research. The participants were often required to question and challenge their own values, beliefs and understanding around quite sensitive issues related to the intimate lives of the research subjects, and this often led to new occasionally unexpected ways of understanding, which needed to be responded to appropriately and with care and consideration.

In closing this introduction I would say that there are clear implications for further research possibilities which will be discussed throughout this study, as well as potential areas for research and enquiry directly related to the specific areas I have examined in this thesis. In Chapter Two, I explore some of the key research that has informed the focus and framework of this study, I provide a brief analysis of some of the current literature available on research around the topics of: disability and identity, sexuality, autism and adolescence and I explore how current thinking within these debates relates to my own research focus.

Chapter 2 Research Context

2:1 Introduction

Outside of the design for the methodological approach used within this project to collect the data, this study has set out to explore a number of key themes. First, the development of sexual identity during the developmental phase [adolescence] for a group of young males with autism. Second, to investigate whether sexual identity formation and forms of self exploration during adolescence have the same meaning for people positioned on the autism spectrum as those reported and understood by people within the neuro-typical community. And third, to look at how identities are developed or in some instances attributed, and the impact of any potentially disabling processes on that development. In this chapter I present a critical assessment of some of the current literature in the field of sexuality and disability studies. The function of this chapter is to present a critical analysis of how the nature and experience of Identity formation within a disabled adolescence is currently conceptualised and responded to within some of the available research. The purpose of this chapter therefore is to identify some of the key research that has informed the focus and construction of this study. Through my analysis of this literature I set my study in context and position it within this burgeoning field of research. In this chapter I explore; what adolescence represents as a developmental phase; the ways in which sexuality is defined and understood; how notions of ability and disability are positioned within that debate and where and how autism as a label fits into these constantly shifting contexts and debates. In short, what sexuality when seen as an integral part of who we are, what we believe, what we feel, and how we respond to others is represented for people with different modes of being and how disabled identities are constructed.

My line of enquiry in this research context chapter therefore covers two separate areas, these are:
- Disabled identities.
- Sexuality, autism and adolescence.

In order to set the context within which this research is located I want to first explore some of the ways in which disabled identities have been theorised and understood by different writers.

2:2 Disabled identities

Lennard Davis (1997:3) writes that 'to understand the disabled body, one must first return to the concept of the norm, the normal body'. Davis asks for any debate around the notion of disability to focus not so much on the construction of disability but rather on the construction of 'normalcy', which can be seen as that which is usual, typical and known or expected. Davis argues that the very term normal is almost impossible to "pin down" and that it is a relatively recent concept that only exists within a certain type of modern industrialised society. The problem, Davis suggests, is not the person with disabilities; the problem is the way in which normalcy is constructed to create the "problem" of the disabled person. However, disability often quite unconsciously, continues to be examined and taught from the perspective of the other. That is, through framing types of bodies as those that fall within the norm and those that fall outside of that category – literally, the others. Through this process of re-framing, what has been created is an artificial 'paradigm of humanity' into which some of us fit neatly, and others fit very badly. Life outside of the paradigm of humanity is likely to be characterized by isolation and abuse (Clapton and Fitzgerald 1997). The challenge therefore within the field of disabilities studies is to shift the focus on to what the study of disability tells us about the production, operation and maintenance of – ableism. Campbell (2008) argues that two core elements are central to what she describes as 'the regime' of ableism. These are first, the notion of the normative and second, the constitutional divide between the normal, the pathological and the mechanisms of ordering (Campbell 2008). The suggestion being that the ways in which disability is seen as atypical and irregular, lead to the promotion of the differential or unequal treatment of people because of actual or presumed disabilities. This positioning of what is deemed normative and non-normative is of particular significance within this study, as a central area of focus within this work is to look at the potential impact of normative interpretations on different ways of being, different sexualities, divergent forms of expression and alternative modes of self identification.

In order to examine and define the ways in which disablism may manifest itself or to

undertake any exploration of what Campbell describes as 'The Ableist Project' I want to begin with an examination of some of the current definitions that presently exist around the term 'ableism' and try to address two key questions:

- How does the notion of the normative (and normative individual) develop?

- How are the fundamental principles that create the divide between what is deemed a perfectly formed naturalised [human] and the deviant [non-human] become enforced?

Chouinard (1997:380) describes ableism 'as a system of ideas, practices, institutions and social relations that presume able-bodidness, and by so doing, construct persons with disabilities as marginalised and largely invisible [others]'.This description firmly places the disabling process very much outside of the lived experience of those deemed [other], viewing ableism as something that exists within the fabric of human relations and as some-thing that happens to this group, something that is applied within a relationship that has one group at the top [abled] and one group at the bottom [disabled]. Campbell (2001:44) refers to ableism as a network of beliefs, processes and practices that produce a particular kind of 'self' and 'body' (the corporeal standard), that is projected as the perfect, species typical and therefore essential and fully human, with disability re-cast as a diminished state of being human.

Within these definitions it is clear to see traces of what McRuer (2002) describes as the ethos of 'compulsory abled-bodidness' showcased for able-bodied performance proceeding from and in accordance with the consuming objects of health, beauty, strength and physical capability. Both Chouinard and Campbell describe within their definitions an organised process that is built around the development of separation and division and within which one [the abled] relates to the other [the dis-abled] from a position of superiority based on – a relationship of difference. Campbell goes on to argue that it is in fact not possible to have this concept of difference and division without 'ableism' and that this divide is extremely deep and something that exists at the levels of ontology, materiality and sentiency. Both Campbell and Chouinard share the belief that they place the emphasis on a conception of ableism as existing within a deeper hub network which functions around shifting interest convergences (Campbell 2008).

Admundson & Taira (2005) attach a far more doctrinal posture to ableism when they suggest that ableism is a doctrine that falsely treats impairment as inherently and naturally horrible and which blames the impairments themselves for the problems experienced by the people who have them. Viewing ableism in this way may have within it some truth, but it could also

be argued that this type of definition dismisses the actual function that ableism has as a social mechanism for promoting and maintaining the central issue of a 'divided relationship', and which the previous authors feel is so important to its fundamental purpose, which is - developing and sustaining a relationship based on division, difference and separateness.

Linton (1998) shares this dogmatic position on what ableism may be, defining it simply as 'the idea that a person's abilities or characteristics are determined by 'disability' and that people with disabilities as a group are inferior to non-disabled people'. Campbell claims: that viewing ableism in this way, as an exercise in comparison, in which each category is discrete, self evident and fixed is potentially problematic and does not take into consideration the important co-relational features of this complex process.

From these definitions then ableism can be viewed as:

- An all encompassing system of 'social relations' with the notion of presumed able-bodidness as its central tenet.
- A network of connections that maintains and supports the concept of a standard human type.
- A conceptual approach which focuses on the central role attributed to the disability/impairment itself.
- A conceptual approach which focuses on the 'connection' that is made between the disability/impairment and the person themselves.

The definitions put forward by Chouinard and Campbell appear to suggest a more socio-cultural understanding of what ableism may represent, which describes an imbedded system through which this 'Ableist project' is maintained, adapted and developed, essentially in order to simply sustain itself. Whereas the more doctrinal positions taken in the last two definitions cited, based within a physical or medical understanding appear to have placed more emphasis on the process of clinical labelling of disability and impairment as the central function of ableism/disablism.

These may act as the two main approaches to identifying [and separating apart] disabled people as a separate group. One approach conceives of disability as the outcome of impairment, viewing it is a form of biological determinism because it focuses on physical

difference. Disabled people are defined as that group of people whose bodies do not work; or look different or act differently; or who cannot do productive work. The key elements of this analysis are performing and conforming, both of which raise the question of 'normality', because this approach assumes a certain normative standard from which disabled people deviate. The alternative approach is that disability `as an entity has been conceived as an outcome of social processes or as a constructed or created category, and that this category will have within it its own separate 'identity' (Shakespeare 1996).

However, Shakespeare suggests that this concept of 'identity' can be used in a reflexive sense, in terms of identifying oneself, which he argues is about staking claim to a membership of a collective or a wider group, and that this 'positioning' of oneself can either be a negative or a positive experience. Writing about identifying disability as a social process, one which promotes and maintains a 'negative' identity Shakespeare (1996) argues that the experience of disability as a negative identity arises out of a process of socialisation, or in the context of social relations, in which impairment is the sole focus of analysis. In the absence of other socially sanctioned identities the 'professional cripple' role may enable successful interaction with professionals, offering the benefits of sympathy and concern on the part of others. As an individualised experience, the structural and cultural context is not challenged, and alternatives to the dominant biomedical paradigm are not available. Shakespeare argues that the person with impairment may have an investment in their own incapacity, because it can become the rationale for their own failure. The legitimation accorded to them by non-disabled people is predicated on accepting responsibility for their own incapacity, and not challenging the dominant order. Indeed, they may become token examples of what has been described as 'the tragedy of disability' (Oliver 2008). Alternatively, various forms of denial may be involved, where a person claims to be `really normal' and tries to minimise the importance of impairment in their lives, perhaps by concealment: in Goffman's (1968) terms, they may try to pass as – normal' (Shakespeare 1996:98). In her social relational model of disability, Thomas (1999:60) redefines disability as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being'. Thus, 'disability' is re-imagined to have political, material, economic, structural, emotional, intimate, and personal dimensions. Redefining disability along these lines, it has been argued, contextualises that

'the oppression disabled people can experience operates on the inside as well as on the outside (Thomas 2004:40 cited in Liddiard 2013). Within this study the subjects attempts at self agency, autonomy and their attempts towards establishing some form of self / sexual identity that has meaning for them is evident in the descriptions provided by the participants. However, within the data are examples of; both supportive contact between the subjects and those that support them alongside descriptions of situations where their acts of identification are occasionally restricted, sometimes re-directed or even constrained.

An alternative way of reframing this position is through adopting an approach to disability which sees it as a positive experience. Goodley (2014:2) suggests that people with labels of profound intellectual disabilities offer us exciting new ways of thinking about our humanness in relation to interdependence, mutuality and interconnection. And that they extend and expand what it means to be human beyond the narrow, normative and rigid view of the neoliberal capitalist self (Kittay, 2002). Goodley (2014:3-4) asks us to recognise the ambivalent relationships that disabled people with intellectual disabilities may have towards traditional notions of the human, and to celebrate the disruptive qualities of disability, whilst acknowledging the complex associations of disablism with other forms of oppression. Re-positioning disability as a 'positive' identity is, Shakespeare (2006) argues, a process of positive self-identification where 'subjection' opens up the possibility of 'subjectification'. This alternative to the negative identification with impairment, is provided by those [disabled] individuals who resist the negative implications of the medical model and who develop a personal response to their impairment which focuses on the exclusion and injustice which characterises disability. On an individual level Shakespeare argues that the ability of a disabled person to do what they wish and their ability to be able to 'action' their lives is directly related to this notion of subjectification, which he states is concerned primarily with;

- How a person is trained into certain ways of behaving
- The extent to which a person is the subject of power over them
- How a person understands their own capacities
- How a person relates to others
- The extent to which the person accepts the situation to be true for themselves personally.

Rosenwasser (2000) suggests that for this process to become operational in both a wider societal sense as well as on an individual basis there needs to be an internalised oppression, an involuntary reaction to oppression which originates outside of one's group. The key factors for this external and internalised oppression then are what have been described as 'negative ontologies' of human significance (perverted sexualities, ambiguous bodies and skins), in this process of 'subjectification' described above which in turn acts as a form of regulatory norm (Campbell 2008). In this manner the ways in which certain human capacities become identified and finalised within particular types of forms in which power creates subjects, may also over time easily become systems of dominance and oppression (Patton 1998:71). Foucault argued that, subjects do not consciously exercise power over their lives, but that they are merely powers passive objects, because subjects are created by power relationships that they do not have any control over (Heller 1996:78). Through this intricate process then of 'subjectification', the notion of the normative (and normative individual) may develop and the fundamental principles that create the divide between what is deemed a perfectly formed naturalised [human] and the aberrant, the unthinkable hybrid [non-human] are generated, imposed and maintained.

Through the combination of these processes and through the synthesis and separation that follows, it is possible to glimpse the workings of a significant inter-relational mechanism, which creates the division necessary to divide the abled from the disabled and which maintains and nourishes the concept of the 'normative' and enforces the fundamental principles of division. Campbell (2008) suggests that the disabled body has a definite place, and it is a place on the threshold between two separate existential places, a place characterised by the dislocation of the established structures that surround it. Not only does it have a position, It also carries out a clear function – it is involved in the dissolution of order through its 'uncontainability' and its 'uncontrollability' and yet it also acts as a formative agent in the continual re-structuring of the way in which institutions and discourses that it comes into contact with represent it. The disabled body she argues secures the 'performative enactment of the normal. The question is, can a positive disabled identity develop within such dislocation? Shakespeare (1996) argues that disability identity is about stories, having the space to tell them, and having an audience which will listen. It is also, he argues, about recognising differences, and isolating the significant attributes and experiences which

constitute 'disability'. These 'disabled' stories can act as a way to disrupt this process of purification by not allowing what they represent to be filtered out. They are not neatly segregated but instead can be viewed as interconnected and representative of wider networks within which notions of a containable form of normality begins to disintegrate and lose its power.

Detienne (1979) describes what may be viewed as 'the double bind' of ableism within western neo-liberal politics, for whilst claiming inclusion, ableism simultaneously reinstates and enshrines itself. Within this position positive signification of disability becomes unspeakable. Returning to the matter of definitional clarity around ableness McRuer writes:

> 'everyone is virtually disabled, both in the sense that able-bodied norms are 'intrinsically impossible to embody' fully and in the sense that able-bodied status is always temporary, disability being the one identity category that all people will embody if they live long enough. What we might call a critical disability position, however, would differ from such a virtually disabled position [to engagements that have] resisted the demands of compulsory able-bodiedness'
>
> (McRuer 2002:95-96)

Maybe it is true that because of the fragile and temporary nature of staying abled, with impending disability a certainty, holding on to a collectively agreed notion of normalness is a necessary device. If this notion of normalness is disrupted by different forms of self-identification, by disruptive sexualities and new forms of body expression then perhaps what is typical, usual, expected and known may change.

2:3 Summary

- Different [disabled] modes of being can offer opportunities to dislocate the established controlling structures that they exist within.
- There is an interconnectivity at play between all actants, those positioned as disabled and those positioned as abled, which casts a new lens on what is appropriate, controllable and containable in human relationships
- Ableist structures and disabling process are measured by the level to which relatedness occurs.

- The key factors for oppression are 'negative ontologies of human significance' which can be located around ideas of sexualities and ambiguity around what the body may represent.

- Ablesism exists within a network and the disabled actant as a [subject] plays a role within that network. The role of [subject] is therefore a vital factor in the way in which ableist processes evolve.

Having explored the theoretical basis from which the idea of abled and disabled identities can be located and developed, I want to now look at some of the available research that currently exists around notions of sexuality and disability as they are experienced for people positioned on the autism spectrum and for people from within the disabled community in general.

2:4 Adolescence, Sexuality and Puberty

Adolescence has long been characterized as a time when individuals begin to explore and examine psychological characteristics of the self in order to discover who they really are, and how they fit into the social world in which they live (Steinberg and Morris 2001:91). Adolescence can be seen as a period of human growth that occurs between childhood and adulthood, with the suggestion being that this phase of transition and change tends to begin at around the age of ten and ends around age twenty one. According to the current dominant medical/psychological theories this developmental stage can be separated into three distinct stages: early adolescence, middle adolescence, and late adolescence (AAP 2017). The first stage occurs from ages ten to fourteen and typically puberty usually begins within this age range. During this stage adolescents become aware of their rapidly changing bodies and start to become aware of their physical appearance. They might experience shyness, modesty and a greater interest in privacy. The second stage tends to occur from ages fifteen to seventeen with this period marked by an intense period of self exploration. Relationships are also often changing during middle adolescence and this period is also often associated with a heightened awareness of the onset of an individual's sexuality. Typically developing middle adolescents complain about their parents preventing them from becoming independent and they withdraw from them. During this phase they may try to find ways to assert their independence (Williams and Roberts 2015). In the third and final stage of this phase, typically developing adolescents move from identifying themselves as an extension of their parents to

recognizing their uniqueness and separation from parents. They develop a sense of self as an individual and as a person; they explore their sense of identity around issues such as gender, their physicality and what their developing sexuality may represent for them (Teipel 2016). However, this idea of an individual passing through a series of stages from childhood to adulthood may not necessarily fit or reflect the lived experiences of disabled people and this period of transformation may indeed not be the same for some abled or disabled people.

An area of interest raised within this study and one which is explored in more detail in Chapter Seven, concerns the effects of puberty on adolescent moodiness, and the role of hormonal changes in emotional development more generally. On the whole, evidence for hormonally driven moodiness in adolescence is weaker than popular stereotypes would tend to suggest, although few studies have examined moodiness (Buchanan et al 1992). Richards & Larson (1993) found no association of average mood or mood variability with puberty among girls, and among boys they found that more advanced pubertal status was associated with positive, not negative, feelings. Also, whereas moodiness may be more characteristic of adolescence than adulthood, it is no more characteristic of adolescence than childhood (Buchanan et al 1992). Changes in mood and the way in which it was felt to have been used by subjects; as a separate form of communication and as a way in which to express / communicate identity was one finding within this study and will be discussed further on in sections two and three.

In this sense then adolescence can be seen as one of the most important of developmental stages for any individual, and one which presents with significant changes occurring across the social, physical and emotional aspects of a person's life (Hayward and Saunders 2010). Greydanus, Rimsza & Newhouse, (2002) and Hellemans et al (2007) have put forward the question: What then are the key developmental tasks of adolescence? And they arrived at these outcomes, stating that adolescence is marked by a series of experiences which include, the establishment of a personal identity, the establishing of a sexual identity, independence and autonomy, the renegotiation of rules, emotional separation from parents, development of social autonomy, taking risks, the demanding of rights, taking responsibility for self - and Intimacy, within some form of sexual relationship or some form of sexual expression.

The central aim of this study was to explore sexual identity formation during adolescence for a group of young men on the autism spectrum, a developmental stage that tends to be

characterised by changes occurring across a range of different areas: emotional, hormonal, social, interpersonal and physiological (Henault 2005). During this developmental phase Individual, family and cultural differences may influence sexual development and sexual behaviour, but for people with autism, according to Griffiths (1999) and Hingsburger (1993) four other key factors have an additional impact on sexual identity formation during this vital period. These are: a lack of socio-sexual knowledge, sexual segregation, inconsistencies in the policies of various establishments and the lack of opportunities for intimacy. Tissot (2009) goes further by stating that there are other certain key factors that have an impact on supporting adolescents in discovering their own sexual identity, [particularly those with autism]. These are: the attitudes of society, the parents/carers personal belief systems, the manifestation of autism in the individual, the type of learning difficulty, the difficulties in teaching 'private' activities and the restrictions placed on the teaching or talking about, or researching of any activity of a sexual nature. Shopler and Mesibov (1993) state that, more wider ranging societal concerns about sex and autism appear to be influenced by two things: Communities fearing the sexuality of the individual with autism and the level to which people support the individual's 'sexual rights'. However, within the Social Model of Disability - the views of society are seen as the most challenging barrier. In fact, societal attitudes may present more hindrances to an adolescent's 'sexual development' than the limitations resulting from the disability itself (Murphy and Young 2005).

2:5 Heteronormativity

Research on young people's lives can often overlook the possibility of different occasionally ambiguous sexual identities, tending to typically assume that young people are always already heterosexual by default. This hetero-normative position, which is based around the belief that people will tend to fall into distinct and complementary genders (male and female) is challenged within this study. Heteronormativity has been defined as a form of enforced compliance with culturally determined heterosexual roles and assumptions about heterosexuality as being 'natural' or 'normal' (Habarth 2013). (King 2016:17) has argued that 'one of the central reasons that heteronormativity has had such a strong and controlling influence over how our culture behaves and constructs itself is that the language [we] use to create reality is inherently hetero-normative'. Clearly within this study the language that is available to define and identify the often highly individualised forms in which the subjects

may represent themselves, does not fully capture the true essence of what their individual 'becoming' as sexual beings may represent for them. Adolescence for the subjects can therefore be re-imagined as a time of friction and transformation that is not bounded by ideas of fitting in, and is not concerned with being labelled as either 'normal', 'male' or 'heterosexual', words that may well have no meaning or relevance either for them or about them.

Griffin (2000) has suggested that this period 'adolescence' is a pivotal moment in which young men and women must be 'won' for the (heterosexual) system. Being placed outside of this system therefore has within it a certain degree of transgression to it and clearly the young men in this study are not constricted by these hetero-normative ideals. What is clear from this study is that we subconsciously learn or are exposed to certain societal messages about how to be and how typical development is expected to proceed. These mold our beliefs, and it is these belief systems that become the lens through which we interpret the world. Building an awareness of our implicit biases is therefore key to interrupting and disrupting hetero-normative thinking (Tompkins 2017). Tolman and McClelland (2011:251) acknowledge the limits of what 'normative' can represent due its potentially moralistic tones, but suggest that its association with what is 'expected' when linked with the increasing acknowledgement of diversity in so many realms of sexuality, signals that part of adolescence may be the very broad task of navigating how to become a healthy sexual adult. Certainly, within this study the pressure that normative ideas of adolescence have brought to bear on the ways in which the different sexualities of the subjects are identified within the data, has often required sensitive negotiation between the participants and myself, and has presented challenges for some of those involved.

However, complexities around using or refuting the label of autism as a defining characteristic when describing normative or non-normative development remains. Gougeon (2010:349) has observed that research continues to pathologize sexuality and disempower autistic people by focussing on their sexual behaviours as being 'issues' or 'problems' typically reported by a third party and always in need of some form of management. While the identified 'problematic autistic behaviours' themselves in many instances often fell within the range of 'normal' behaviours found within the rest of the population. Realmuto and Ruble (1999) have also located this dilemma when they write that while autistic people face a number of

obstacles in learning and expressing 'normative' socio-sexual behaviour, social perceptions exacerbate this idea of problematization. In particular they observed that many behaviours labelled as 'problematic' are simply part of typical sexual development and are common in children. Children 'grow out' of these behaviours as they learn socio-sexual norms through peer interaction and formal educational. However, people with autism are often excluded from these educational opportunities, particularly the social learning opportunities that are key to gaining knowledge about norms for sexualised or intimate interactions (Koller 2000, Mehzabin and Stokes 2011, Stokes Newton and Kaur 2007, Realmuto and Ruble 1999, Tissot 2009).

The danger in aligning myself to any form of heteronormativity in my analysis is something that I have attempted to address throughout this study. Clearly, we live in a hetero-normative world, and the subjects within this study spend their days in classrooms and homes that are extensions of the world outside them. The messages that they receive inside and outside of these spaces often puts forward a hetero-normative worldview and this undoubtedly impacts on both them, those caring for them and the systems and policies of the places they attend. There is then a level of supportive 'protection' required from those people who support these young men, as they develop and express their own forms of sexuality. The level to which [hetero] normative ideas of what those sexualities may look like, what is permitted or restricted and how that impacts on that expression is what I have set out to explore in this study.

2:6 Sexuality disability and autism

Research around Sexuality and Learning Disability has been an area that has traditionally received very little exposure and attention, as it is often potentially thick with complex moral and ethical issues around consent and sexual disclosure. A central area of investigation within this particular research study was the impact of a developing sexuality on a group of adolescent boys with autism, as a researcher attempting to find a sensitive and ethical model from which to begin an exploration of what sexuality may represent for the subjects within this study, I came into direct conflict with these barriers. Currently there is very little qualitative research evidence on what 'sexuality' for people with different developmental profiles may mean to them, and even less on the numerically fewer individuals on the autism

spectrum. This may be due partly to the commonly held misconception about people with both of these types of developmental difficulties, who are generally seen as either 'sexually immature' or as 'asexual' '(Konstantareas and Lunsky 1997:398), or too vulnerable to take part in sensitive research of this type.

When attempting to find a meaningful response to the question 'what is sexuality' within the framework of people with autism there is a need to first consider the definition. "Sexuality" when applied to people with autism is often narrowly defined and tends to focus on behaviour. From this position such stringent behavioural definitions can act as a way in which to diminish the element of emotional intimacy that can accompany sexual expression. (Realmuto and Ruble 1999). For young people with autism, who struggle to make clear connections and who may not be able to access standard typical forms of communication efficiently, this developmental phase can become extremely problematic and highly confusing (Lawson, 2004). To begin with, in order to address potential prejudices around what or what does not constitute a developing sexual identity or what different forms of sexualised behaviour may be, it is worth considering five premises of the philosophy of adolescent and adult sexuality as it relates to people with autism;

- There is no positive correlation between knowledge of, and interest in, sexuality.
- Adolescence is a period marked by curiosity and exploration; this phase of development is completely healthy.
- Urges and desires cannot be repressed; they must be directed towards appropriate expression.
- Behaviour is less likely to be excessive if it is recognised, accepted, and appropriate in a given context, rather than forbidden.
- Ignorance breeds fear, information allows an individual on the autism spectrum to develop their own judgement and puts them in a position to react better to a variety of situations (Henault 2005).

These points are worth bearing in mind as we move forward to examine the extracts in both this section and section two, primarily because knowledge as a shared experience that the parent and staff participants may have access to; may be qualitatively different to the highly

personalised form of individual knowledge each of the subjects may have about their own bodies and the bodies of others.

Within any investigation of what sexuality may represent for autistic people there are also the notions of 'personal care', 'appropriateness' and 'context' which need to be explored, as these concepts may potentially represent something very different or very little to someone with a different understanding of the changes that their body is undergoing. From this position, the acquisition and development of an individual 'sexuality' or a 'sexual persona' and the free expression of it, can potentially therefore become an experience of disempowerment for some young adults with autism. For people with autism sexual behaviour may therefore have a range of different contexts:

- It may be the only source of pleasure, excitement or gratification available to the person.
- It may serve as a way to reduce "anxiety".
- It may have the same value as any other behaviour the person exhibits.
- It can allow the young person to feel a sense of security in a routine.
- Sexual activity of any form may stimulate the sensory organs and create arousal.

From this, there are a number of explanations for why sexual behaviours of concern may occur:

- Inappropriate sexual conduct becomes the only alternative to seeking relationships.
- A young person tries to copy an observed adult sexual behaviour.
- Attempts to initiate connections with peers using forms of sexual expression and behaviours.
- Experiences of sexual abuse
- Some medications can affect libido, sexual interest or drive. Others can make arousal and ejaculation difficult which may increase tendency towards compulsive masturbation and other sexual behaviours (Adapted from Lee, 2004 and Ray, Marks & Bray-Garretson 2004)

It has been argued that although children on the autism spectrum may be delayed in other areas of development, they will typically experience puberty, adolescence and all that goes

with that at the same time as everyone else in some form. This is absolutely typical and to be expected. However, the likelihood is that they are going to need extra support in these areas because of difficulties around understanding social rules and the limited opportunities they will have to learn from other children (Hartman 2014:1). Stokes, Newton & Kaur (2007) argue that adolescents with autism have the same sexual desires and fantasies as people who do not have autism and that the success or failure encountered by young people from within this group during their sexual development can impact upon their ability to effectively transition into adulthood. It is also suggested that young people with autism undergo typical physical development during puberty but that the emotional changes and the increasing sexual urges that accompany adolescence may in some cases be delayed or perhaps even prolonged (Sullivan & Caterino, 2008). This delay or deferment of what adolescence can bring and what it may represent can raise issues for these young people and for those supporting them.

A study carried out by Ray, Marks & Bray-Garretson (2004) suggests that for people with autism sexual behaviour simply 'feels good' and what others may think about it takes a secondary position. Arguably, it is these direct forms of sexual behaviour that are generally of concern to parents and carers. They are often seen as being in some way related to what are often described as the core impairments of autism, including perceived difficulties with social knowledge, around reciprocal interaction and communication and issues around considering the viewpoints of others.

Some writers who identify with a position on the autism spectrum have provided their own personal views around the experience of 'adolescence' and 'sexuality'. O'Neil (1999:98) states that, 'autistic teenagers do have sexual stirrings within them, and that they can become interested in the other sex. They do not always know how to approach members of the other sex, she states, but they can be coached gently on how they can do so. Yet they must always be allowed to be themselves – and they will always be different' Lawson argues that 'the neuro-typical world would do well to look within its own ranks to prevent their members from misusing their own sexuality before they lay claim as to what to do with people on the autism spectrum. Sexuality is part of being human, she states and as such should be rightly appropriated by all of us (Lawson 2004:31). Jackson a teenager with Asperger's syndrome offers his own perspective on 'fitting in' to a neuro-typical world, when he states,

'I think society and its way of shaping people and making them conform is rather pathetic, it seems to me that society as a whole is actually more rigid than people with autism. Having an autistic kid in the family can actually be very good for the whole family, because it must make parents and relatives consider and even revise their whole way of looking at the world '.   (Jackson 2002:171)

Johnson (1987) states that sexuality when applied to a person with autism has often been narrowly defined and tends to focus on behaviour. When viewed in this way the emotional and the psychological elements of sexual expression are diminished; looking simply at 'behaviour' does little to inform a public with a low tolerance to inappropriate sexual behaviours.

Through carrying out an examination of some of the problems around definition of sexual behaviour in people with autism Realto and Ruble (1999) suggest that sexual development for individuals with autism is an area that has remained largely unexplored and that with the limitations in our understanding that currently exist, sexual expression in individuals with autism can easily be mistaken as 'deviant'. Coupled with this, misunderstandings of behaviour, poor social skills, restrictive community standards for sexual expression, and fear based largely on ignorance may also significantly influence other areas such as program participation and administrative decision making (Yacoub and Hall 1999). For this specific group socially unacceptable sexual behaviours were related directly to core features of autism such as, impairment in social awareness and reciprocal interaction, which it was felt could lead to errors in social judgement (Ruble and Dalrymple 1993). Difficulties in learning adaptive social behaviours in an unstructured fashion (Ferrara and Hill, 1980), difficulties in recognising subtle affective cues (Hobson, 1986), communicating accurately and competently with others (Wetherby 1986), and finally, the development of a 'Theory or Mind', that is; taking the perspectives of others and considering both their own and others viewpoints (Baron Cohen et al, 1985).

These can all be seen as factors which may or may not impact on the way in which any form of potentially sexualised identity was developed. Learning about sexuality is also often seen as an area that children learn about through socialising with their peers in their own social cliques and adolescents with autism are most likely to be excluded from this process (Adams

and Sheslow, 1983). For these authors therefore, these aspects were all viewed very much as 'disabling' characteristics that they believed were specific to the autism spectrum and which helped to complicate and delay positive sexual development and contribute to what could be defined as 'inappropriate sexualised behaviours'. This presents a setting which illustrates how negative connotations around sexual expression can impede any form of positive personal experience of being an adolescent with autism, trying to come to terms with a changing occasionally unwieldy body.

The dominant approach to sexuality in autistic people seems therefore to be essentially problem-centred. Topics generally tend to include; acceptability of sexual expression to others; risk of diseases or abuse; excessive masturbation; inefficient masturbation and self harm connected with masturbation (Mortlock, 1993, and Howlin, 1997). Behavioural issues in relation to masturbation (i.e. children masturbating at inappropriate times or places) are commonly reported in special education settings and by parents alike. This is wholly understandable, given that it is developmentally a typical behaviour resulting in immediate feelings which are intensely pleasurable, and therefore far more strongly reinforcing and immediate than other types of reinforcement (Hartman 2014:162). Masturbation is the most common sexual behaviour reported by adolescents on the autism spectrum and can be characterised as any form of self stimulation. However, behavioural problems related to masturbation are often observed in individuals with autism (Hellemans and Deboutte 2002). Couple that with the difficulties that children on the autism spectrum are reported to have in understanding the social rules that can govern their behaviour, and issues will naturally arise. However, unfortunately, the topic of masturbation for people with disability / autism is still not an easy one for open discussion due to strong social taboos, and often it is parents' and professionals' personal values in relation to masturbation that determines whether [and how] these issues are addressed (Cambridge, Carnaby and McCarthy 2003).

This raises questions around how much access to appropriately supported spaces during the day; both at home, at school and in any other care settings that young autistic people have so that they can explore their bodies privately and away from the scrutiny of others. During adolescence, auto-eroticism is the most common source of sexual satisfaction, and masturbation rates of 75% to 93% have been reported in the general population (Haracopos and Petersen, 1992). Masturbation is also the most frequent sexual behaviour for individuals

on the autism spectrum who are not looking for interpersonal physical or sexual contact (Aston 2001). From within this group males tended to masturbate but were still quite frustrated because their desire remained. However, the topic of masturbation remains one that is still of primary importance for these subjects and one that I will revisit in section two.

The WHO (World health Organisation) has defined sexuality as in the following way: 'Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed' (WHO, 2006:5). The literature that currently exists around sexuality and disability appears to describe a situation where by people with learning difficulties [or specifically for this study people with autism] are denied the opportunity to develop a sexual identity or are stopped from expressing their sexual self, simply because it is seen as; very difficult to manage, leading to socially inappropriate situations or is liable to bring about even more complex challenging sexual behaviours. And from this situation does it just become another manifestation of deviance?

Over the past 30 years there has been a growth in the literature relating to the emergence of certain characteristics within young people on the autism spectrum during adolescence, much of it located within a highly medicalised / behavioural model that focuses on what people with autism do and how their behaviour impacts upon others rather than trying to reach understandings of how the changing body is experienced by young autistic people themselves. This approach is rooted in its emphasis on 'clinical diagnosis' and treatment, focuses primarily on individual impairment, deficit and disadvantage, particularly as related to functional loss (Rothman 2003). Much of this literature on disability assumes that disabled people are either 'asexual', or it simply uses 'hetero-normative models' that completely ignore the sexual identity development and range of identities and forms of expression of disabled people (Grossman et al 2004, O'Toole 2000, Tepper 2000).

It is of interest to note that up to 30% of people with autism experience an increase in what have been described as behaviours of concern during adolescence (Eaves & Ho, 1996) and that some of these changes associated with aggressive behaviour and sexuality can be

attributed in some way to changes in hormones (Biro & Dorn, 2006). Backeljauw, Rose & Lawson (2004) note that sex steroid production in the body during this developmental stage is accompanied by the occurrence of sexual feelings similar to those experienced by adolescents without disabilities, and yet descriptions of behaviours of adolescents with autism viewed as inappropriate, challenging and difficult continue to persist. These behaviours may be no different between autistic and non-autistic adolescents, but for one group they are made deviant and in need of suppression while for the other group generally they are not.

It has also been suggested that sexual negotiations are best understood in relation to the micro-contexts in which they occur Aggleton (1998). And that, young people's experiences and learning around these types of negotiations relates to the embeddedness of their identity and the amount of practice they have in social relations with others around time spent in certain key spaces (Giddens 1991, Dowsett 1999 as cited in Hirst 2004). That sexual identity coheres around negotiations around key spaces [bedrooms, toilets, showers]; key times [bedtime, bath time, dressing and undressing times] and through the negotiation of interaction and communication with people is a core theme within this study and is explored in Section Two.

Some of these themes are visible in this selection of studies below and indicate a tension within the literature that I sought to address through this research study. A series of research studies carried out by De myer 1979; Kempton 1993; Haracopos & Pedersen 1992 established that between 63% to 97% of autistic individuals masturbate. Another study (Van Bourgondien, Palmer & Reichle 1997) found that 34% of young autistic individuals had attempted deep kissing, caressing and interpersonal genital contact. And yet another study carried out by Konstantareas & Lunsky in 1997 found that 26% had experienced 'sexual relations' and that 46% had tried a variety of other – 'sexual behaviours'. Hellmans and Deboutte (2002) in a series of six studies, found that most young men on the autistic spectrum between the age of 18 to 22, had experienced 'caressing' and 'kissing', and that 40% of those within the group had given or received what this study described as a 'sexual' touch'. Yet another study by Gray, Ruble & Dalrymple in 1996 revealed that 60% of the adolescents with autism within their group of research participants displayed 'sexual behaviours' and that 35% of these adolescents displayed behaviours that were defined by others as 'inappropriate'.

In a very real sense I would argue that this medical model does not in any way address the social environment barriers (the existing values beliefs of the people who have power over the lives of disabled people) or the demographic factors (race, ethnicity, gender, sexual orientation, age and religion) that may impact on an individual's functioning and identity development (Shulz 2009). These studies clearly assert that physical and inter-personal self exploration during adolescence is identifiable within the experiences of adolescents on the autistic spectrum. However, what is clearly identifiable from these studies, is that very little is recorded about how this is actually experienced personally [qualitatively] by people with autism and even less information exists to describe the experiences of those who are not accessing language at all and therefore cannot share their experiences through this mode.

Some of the specific issues that are believed to be associated specifically to people positioned on the autism spectrum as they relate to forms of sexual expression and sexualised behaviour are seen in the work of these writers. Differences in understanding around social awareness and reciprocal social interaction, necessary for learning and understanding appropriate sexual interaction can lead to errors in social judgement (Hayward and Saunders 2010). These errors in social judgement may interfere with the ability to assess whether they should perform certain behaviours in public or private places and how and why they should practise personal hygiene (Kalyva 2010). There may be difficulty learning how to interact with others, recognising subtle cues, communicating with others and considering their own and others' viewpoints (Realmuto & Ruble, 1999). Some young people with autism may have an excessive curiosity about the human body and the way it functions (Lee, 2004). (Ray, Marks & Bray-Garretson, 2004) argue that sexual behaviour feels good and that what others may think about it takes a secondary position to people with autism. In terms of the subject's in this study, the key factors that led the participants to interpreting behaviours as sexual was any incident or experience that involved: touching of genitals; touching of other people in a way that was described as inappropriate and linked with arousal; objectifying a person or thing as something that the subject found arousing; masturbation and a subtle change in the mood of the subject typically described as some form of arousal brought on by proximity to another person.

There are therefore indications of clear barriers around any real understanding of what sexuality may represent for people on the autism spectrum. There is evidence to show that

often severe limitations are placed on people with autism by a society that has traditionally located them very much within a 'disabling' medical model; one that views autistic people as different, and in some way set outside of the a typically accepted ways of being.

2:7 Summary and Research Questions

- People with autism may experience their own sexuality in a variety of different ways, some of which may be highly individualised and which can often bring them into conflict with the people supporting them and in a wider sense with society in general.

- Ideas of difference are often pathologised by focussing on perceived 'autistic traits' such as; differences in understanding around social awareness and reciprocal social interaction, a lack of understanding around what is appropriate and inappropriate, heightened sensory awareness, difficulties in linking concepts, issues around communication.

- This phase also represents a time of change and re-negotiation for parents and carers.

- The strategic role played by parents and carers is a critical factor and one that highlights the interconnected nature of this phase.

In this chapter I have explored some of the different ways in which writers working within the field of disability research have framed the processes through which disabled people are often marginalised, and disempowered. I have examined how sexuality for disabled people has been researched and understood, and how sexuality can also become an area of control and disempowerment that people with different ways of being have to negotiate. This study has attempted to address these positions by placing the subjects at the centre of the analysis and by providing a type of research space that allows notions of sexuality and sexual identity to be freely discussed.

In concluding this chapter I restate my original research questions, which asked:

1. Does sexual identity formation and self exploration during adolescence, have the same meaning for people with autism as it does for those reported by people within the neuro-typical community?

2. Do the individual interpretations of the participants within this study, and the meanings

they attribute to the actions and behaviours they observe have an 'enabling' or 'disabling' impact on the young men at the centre of this research?

3. Is it possible to construct a reliable research methodology that would provide a way of accessing and capturing the 'essence' of the lived experiences of people with different and divergent forms of articulacy?

In the following chapter I present a detailed description of the methodology that I have used for this study within which I have attempted to locate the voices of the research subjects and in doing so elevate their involvement and participation. I explore some of the methodological issues that I have faced in getting this study underway, and I discuss both the role of the subject and the role of the participants within the research process.

Chapter 3 Methodology

3:1 Introduction

In this chapter I provide a systematic examination of the design for the methodology used in this project, and I explore some of the tensions, possibilities and practical challenges that I faced when developing and using this methodology to gather data. It has been argued that good quality research would ideally always 'use a systematic and rigorous approach that would aim to answer questions concerned with what something is like, what people think about something or what they feel about the way in which something has happened, and how it may address why something has happened as it has' (Seers 2011:121). Shelton (1999) states that a key aspect of research is that there ought to be a systematic design in advance, generally utilizing a scientific approach or protocol, for the definitive purpose of contributing to generalizable knowledge. Generally in descriptive phenomenology research steps are made explicit and sequential, which allows them to be replicated by other researchers (Finlay 2016). In fact when attempting to evaluate and examine any individual experience, any action or interaction phenomenology asks the researcher to consider questions such as "What is this kind of experience like?", "What does the experience mean?", "How does the lived world present itself to me?" Phenomenological research focuses on the subjective experience of the individual and the meanings that people make of their experience, and it asks the researcher to consider "What is their experience like for them?" And, "How will it be possible to understand and describe what happens to them from their own point of view?" (Robson 2002:195). Within this study one of my central aims was to explore how meanings were arrived at for people who could not communicate their point of view, and critical information about who they were to others. And to examine whether the interpretations, understandings and descriptions of [significant] others were in fact reliable and valid ways in which to represent people who could not influence these decisions.

Where the previous chapter has acted as a way in which to provide the context within which the research for this study was conducted, the purpose of this chapter is: To explain how the conceptual understanding gained from the literature (both literature discussed in chapter two and in this chapter) have informed the design of the research methodology used in this project. To present a detailed description of the research methodology and a scrutiny of each stage of the design of the methodology, and to present the reasons behind the decision to

combine an adapted form of Lifeworld with a thematic analysis of the data - and to look at how this impacts on:

- The positioning of the subjects within the research as it unfolds and the way in which they were represented.
- The role of the participants in the research process.
- The form in which the personal stories of the participants and the subjects are individually and collectively represented in the data.

3:2 Participant and Subject

Within this work the young men who were initially highlighted by the staff within the school and by some of the parents as presenting with behaviours that were universally described as 'sexualised' will be referred to as the [subjects]. Those members of staff and the parents who agreed to take part in this project are referred to as the [participants]. Below I provide a brief definition of the way in which I have used each of these phrases, as they have a specific meaning within the research process that requires clarification.

Subject: Within any research typically the term 'subject' is defined as describing an individual about whom an investigator conducting research obtains data about, through a process of interaction (ORIA 2016). However, uniquely the young men within this study from their position of being the subjects, challenges this position of being the individual that data is obtained from. Their role within this study is different, as their actions and reactions provide one of the central areas of focus in this investigation. It is the interpretations of the participants that are explored in this study and the material that forms these interpretations is drawn directly from the subjects. In this sense the research subject is no longer regarded as a passive object to be studied, being kept in the dark about the research and its objectives and simply 'responding', but as a valued partner in an exploratory process (Suri 2011), despite the fact that their role may be viewed as passive and unreceptive. The subject's stories are vital to this study and to a greater or lesser extent the stories of the subjects within this study reside within the stories of others. How effectively the young men within this study have been included within the research process and whether or not their participation has become visible is of importance to this researcher. Issues around this position of the subjects being

passive partners within the research or active participants are discussed in Section Three [Chapter Nine and Ten].

Participant: As it is used in this study the term 'participant' is somewhat murky and to some extent a little indistinct, as it requires the parent or staff member taking part in the research 'to both combine the role of participation in the lives of the people being studied whilst maintaining a sense of distance that allows adequate observation and recording of [the] data' (Fetterman 1998:34-35). It also underscores the person's role as a contributor themselves within the social setting he or she observes (Gold 1958 ; Adler and Adler 1987). The staff and carers were asked to reflect on situations that they may well have played a key role in developing, which placed them in a position of commenting on features of the subject's lives that they themselves may have helped to construct and maintain. In this study accessing the meanings of experience for the subjects is mediated through challenging the understandings and the interpretations of those around them. The focus was throughout on supporting the participants to try to express the world of the subjects. This interplay between subject and participant is explored throughout this study as it raises questions around 'who is the researcher' and 'who is being researched', that have implications for the way in which meaning is arrived at and how ideas around interpretation and analysis are understood.

3:3 Theoretical Approaches

There are two main bodies of theory which will be informed by this study and which also inform this study: These are the Social Model of Disability and Lifeworld.

The Social Model of Disability

The social model arose in response to the medical model of disability, and it has generated a gathering of academic writing, predominantly written by academics and activists who themselves have disabilities and is the total antithesis to the medical model. The primary focus of analysis is the manner in which the social model shifts away from consideration of the deficits of the functional, physiological and cognitive abilities of the impaired individual, to the ability of society to systematically oppress and discriminate against disabled people, and the negative social attitudes encountered by disabled people throughout their everyday lives (Lang 2001:3). The social model of disability was developed by disabled people

themselves and looks at the barriers erected by society in terms of disabled people being able to participate fully in day to day life. It seeks to remove unnecessary barriers which prevent disabled people participating in society and living independently. This model recognises that attitudes towards disabled people can create unnecessary barriers to inclusion and requires people to take proactive action to remove these barriers (PHSO 2017*).* The social model of disability proposes that systemic barriers, negative attitudes and exclusion by society are the ultimate factors defining who is disabled and who is not in our society, and a fundamental aspect of this social model is concerned with equality and empowerment and emancipation for those marginalised, not by any individual difference – but instead by the effects listed above. The social model is the Disabled people's movement's key to dismantling the traditional conception of impairment as 'personal tragedy' and the oppression it bequeaths (Crow 1992:2). In attempting to define this model Shakespeare (2002) argues that disability is now defined, not in functional terms, but as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments; learning difficulties; social and emotional impairments and thus excludes them from participation in the mainstream of social activities. This theoretical model states that attempts to change, 'fix' or 'cure' individuals, especially if the individual has no understanding of what is happening (SAIL 2017), has the potential to be discriminatory and that it can harm the self-esteem and level of social inclusion of the person. The methodological approach used in this study resides firmly within this social model of disability, in that it has attempted to locate the voices of the subjects, bringing their lived experiences to the fore and situating them within the research process as actors within the stories that have unfolded and become available. Through giving primacy to these hidden voices the highly individualised forms of self validation employed by the subjects have become known and their power explored.

Lifeworld

Lifeworld is an existential phenomenological methodology that is concerned with human experience and the various meanings people attach to what happens to them (Wilson 2002; Ashworth 2003). Lifeworld was originally described by Husserl as the foundation for all human science research (Husserl 1900), and then later it was developed as a practical philosophy for understanding human existence (Gadamer 1989). Husserl was concerned with developing

phenomenology as a rigorous alternative to methods traditionally used by the natural sciences. These existing methods were, Husserl believed, inappropriate for the examination of human experience. In contrast to notions of an objective reality, Husserl suggests that it is in fact only our experience of the world – namely, direct and subjective human experience – that is 'knowable' (Brooks 2015:642). This approach uses the 'personal accounts' of people to assist with the complex task of interpreting the behaviour of others and it requires the researcher to remain open and available to all of the factors that might influence the lived experiences of the participants they are engaging with (Hodge 2008). This research model works primarily through maintaining a central focus on the actual 'individual experiences' of the participants, giving value to these lived experiences while making no attempt to extract essential, universal truths or common theories (Hodge 2008). Lifeworld as a methodology has been used as a means of identifying such imbalances of power, by giving expression to those traditionally without a voice (Hodge 2008). Within this study I have not attempted to use Lifeworld as a complete methodology, but instead have used it in conjunction with the 'fractions' (Ashworth 2003) as a tool to help with the categorisation of the data. This approach can provide a platform from which these often hidden stories can become known, can become shared and validated, and this is a primary reason for using such a methodology in this study. One of the key aims of this study, is that through its use of lifeworld, this study will give value to the subject's experiences, and will be a means by which disabling barriers will be identified, and that these 'experiences' will be acceptable as units of evidence, when attempting to interpret the behaviours of the subjects at the centre of this study.

Some of the questions raised here point towards the ways in which we understand our own unique way of being and how we make sense of what we experience, and asks us to consider - how do we come to understand and make sense of the experience of others? Through this phenomenological approach, within which this particular research project firmly resides, the focus is placed wholly on trying to capture and identify an elusive unit of meaning; that is - understanding and describing the 'essence' of the lived experience, the intrinsic nature or indispensable quality of something, which determines its character. Dahlberg (2006:15) argues that 'describing essences is a clarification of meaning as it is given. This usually occurs through the study of several individuals or a small group that have a shared experience, using - primarily - interviews with individuals, and analysing the data for significant statements,

meaning units, textural and structural descriptions and descriptions of the 'essence'(Creswell 2007:78). The challenge for researchers using any type of phenomenological approach is therefore twofold: First, how to help participants to express their world as directly as possible. In this study I am exploring the meanings that one group have attributed to another group, and have accessed the meanings of experience for this other group [the subjects] mediated through the challenged understandings of those around them [the participants]. Second; how it may be possible to explicate these dimensions in order that the lived world – the Lifeworld – is revealed' (Finlay 2008:2). The focus of this study therefore, is not about helping participants to express their world but instead it turns the focus inwards on supporting participants to express the world of the subjects. In this study uniquely, accessing the meanings of experience for the subjects is mediated through the challenged understandings of those around them. Within these understandings resides the interpretations of the communicative material presented by the subjects and it was through a process of sensitive challenge and through revisiting the responses of the participants that the subjects voices began to be accessible. An exploration of how the ethical issues raised within this study were managed throughout its duration are examined throughout this work, however for more information please see the documentation for ethical approval provided in [appendix 5 page 243].

In the following sections of this chapter I present a step by step breakdown of the different stages that made up each of the separate initial phases of this study. The first stage of the study entailed the selection and recruitment of the participants and from that the subjects who were going to take part.

3:4 Stage One: Selection and Recruitment

- Arriving at a selection criterion.
- Locating the subjects from within the population of the school.
- Recruitment of parents / receiving consent to use students as a focus for enquiry.
- Recruitment of staff.
- Recruitment Group meetings / 1:1 individual recruitment meetings with participants.

3:4:1 Selection Criteria

Pre-recruitment stage

It was expected that data collection for this study was likely to take between eight to ten months, and that it would take place across a series of separate stages following the selection of the students and the recruitment of the participants. Without formally approaching any of the staff or parents, in order to begin this process of selection I had started to consider which individuals could potentially play a role as participants within this project. These potential participants I believed would probably emerge from those that had already reported to me formally and informally about some of the issues that had been identified and which this study would attempt to explore. I began to raise the issues reported to me in a series of informal staff meetings in the school, in order to gauge interest and the level of commitment from within the school around providing some form of support for the students, staff and families. Following my successful application for ethical approval for my study I informed the staff and a selected group of parents that I was intending to develop a piece of research around some of the issues that were being reported to me at that time and that I was looking for people to play a role in it if they were interested.

I raised the idea of this in a whole school staff meeting and in informal conversations with some of the parents, outlining; what I was looking into; how I initially intended to carry out the research and exactly what may be expected of any staff or parent that wanted to take part. From this, a number of staff and parents approached me personally and indicated their interest in taking part in the project. I had informally started to create a group of potential student subjects from within the school population that would form the core group from which the study could begin. At the time there were nineteen students within this cohort who fell within what ended up becoming the defining selection criteria for this project.

3:4:2 Locating the subjects

For the subjects, the selection criteria for the study were;

- A student who had a clinical diagnosis of autism.

- Who does not access typical forms of communication efficiently, typically positioned below or at P3 [appendix 11 page 289]

- Aged 12 to 16.

- Who had been described by staff or parents as exhibiting what they described as 'sexualised behaviour'.

- Who had been described by staff or parents as exhibiting what they described as 'challenging behaviour'.

- All of the subjects involved in this study were male, the epistemological reasons for this are discussed in Section Three.

Through my personal contact with these young men, and through conversations with their parents and with the staff who supported them in the school, I already had concerns that the types of behaviours that were being reported and the level of distress that the students were experiencing was raising significant concerns for all those involved in their care. I therefore wanted to use this study as an opportunity for an in depth enquiry to explore; what the issues around this developmental phase [adolescence] may be; how I may be able to develop an understanding of how the issues being reported around their behaviours might have arisen; and what experiences these young men may be encountering.

Once the student subjects had been selected as a group, the participants naturally became the parents and staff directly associated with these young men. This initial recruitment stage was then carried out in three separate stages.

3:4:3 Recruitment

Recruitment has been described as the dialogue which takes place between an investigator and a potential participant prior to the initiation of the consent process. It begins with the identification, targeting and enlistment of participants for a research study, and it involves providing information to the potential participants and from this, generating their interest in the proposed study. It has been argued that few participants will take part in research unless they can identify with and understand its validity and relevance. Consequently, an adequate, clear and concise explanation must be provided. It is also important to take into account that retention of participants once they have been recruited is a related and important aspect of recruitment. Nishimoto (1998) argues that early retention techniques should be incorporated

into recruitment strategies during the planning phase of the study and that this builds strong relationships with participants and encourages their continuing participation.

3:4:4 Parents

All of the parents whose sons fell within the selection criteria for this study were provided with a recruitment letter (appendix 1 page 234), which they were asked to complete and return. One participant was the subject's aunt who had taken on the role of primary carer, and for that reason and with her agreement I have incorporated her into the group I describe as parents. The letters were sent out to the potential participants individually. Within the letter was an explanation of; exactly how the project was going to run, how long it would last and what each participant's' involvement would entail. Bell (1993) and Miller et al (1998) suggest that it is essential to seek permission at an early stage in order to carry out a study; and that potential collaborators need to know exactly what they will be asked to do, how much time they will be expected to give and what use will be made of the information they provide. They stress that; all potential participants will have to be convinced of the researcher's integrity and the value of the research before they decide whether or not to cooperate.

In this initial phase, there was also an open invitation for all parents who had been contacted to attend a meeting with me for more details and information about the project. It was made clear that if they did choose to take part, there would be an introductory meeting of all parents where everybody could meet up and ask any questions they had. The letter also explained that if any parents wanted to take part but preferred to meet with me privately to discuss these issues, then that would be arranged on an individual basis.

At this stage it was made clear that from the outset through accepting to take part in this study parents were giving consent for their sons to be: involved in this study; spoken about and discussed either individually with me or within the group meetings; and that their sons would be a central focus of enquiry within the project. Hulley et al (2001) argue that respect for the participants during this initial phase requires a high level of ethical consideration from any researcher, and this required me to obtain informed consent in a form that parents could understand; to consider how I might make information accessible to all parents and; to

consistently maintain confidentiality. At this stage it was also made clear in the letter that these young men would be discussed separately by members of staff within the school who would also be invited to take part in the project, but who would have no involvement or contact with the parents who had agreed to participate.

My decision to have two separate groups, one of staff participants and one of parent participants, was arrived at because of a number of different reasons. First, I felt that the parents needed some anonymity in terms of their role within the study, as some of the content of the meetings may expose certain areas of their private lives that they may not wish to share with the staff working with their sons. Second, I felt that the staff participants may feel uncertain or uneasy about speaking frankly about the student subjects in the way that they may wish to, if the parents were in the room with them. Third, the staff all work together, know each other well and have shared experience of the students and I felt that they would feel comfortable in sharing both current and past experiences of working with these students, and that conversation would flow. Fourth, the parents had met each other in previous parents' group meetings at the school and knew each other to some extent through these forums. From my experience it was clear to see that there appeared to be a real feeling of camaraderie between the parents when they met together, and a sense of shared understanding that was palpable and distinctly their own experience. Fifth, my concern was that as the study proceeded if parents and staff were meeting jointly both groups may inadvertently censor or alter what they were saying and that their responses may become warped or distorted in some way simply through being with each other in a group setting.

The recruitment letter also offered potential participants who may have wished to take part, the opportunity to agree to involvement in the study whilst remaining anonymous from other participants. For these participants any further involvement they had in the research process would take the form of individual one to one meetings negotiated with me. In this way participants were able to take part in the entire study without their identity or involvement being revealed to any of the other participants, if they so wished. The parents were provided with a blank return envelope, and advised that they could return the letter back to the school at the reception desk in an unmarked box that I had placed there.

From the nineteen parents who were initially invited to participate, six parents agreed to take part in the study, and through their agreement to take part their five sons accordingly became the subjects within the study [two of the people who agreed to take part were a married couple].

From this set of parents, all six wanted to take part in the one to one interviews but none of them wanted to attend the group meetings. At this stage in the study I did not want to ask why they preferred not to attend the group meetings, as I felt that their acceptance to take part for a study that was expected to last one year was significant in itself, but made it clear that these meetings were still available for all parent participants and that this would be facilitated over the duration of the study if and when required. The reasons why only six out of the nineteen parents invited agreed to take part may be linked to: The length of time participants were expected to engage with the study; the potentially sensitive nature of the type of conversations that may develop in the interviews; confidentiality around what is said and what is known about the parent participants' private life; the pressure of having to attend interview meetings at school; the pressure of allowing a researcher into your home on a regular basis for one year; child care difficulties; and fear around what becomes known outside of the family about the ways in which sexuality and sexual expression are understood by the family. The thirteen potential participants that decided not to engage with this study were provided with ongoing support around the issues that were under examination through the usual school support systems, this took the form of: SRE (Sex and Relationship Education) parents' forums, access to training courses on SRE, targeted parent meetings around topics related to SRE chosen by parents, and ongoing teacher support.

Below in fig:1 I have presented a chart which shows the individual characteristics of the parent participants who agreed to take part.

3:4:5 [fig 1: Demographic breakdown of parent / family participants]

Participants	Gender	Relationship	Socio Economic position
Parent A	Female	Mother	A1
Parent B	Female	Mother	C1
Parent C	Female	Mother	E
Parent D	Female	Aunt [Primary Carer]	D
Parent E	Female	Mother	E
Parent F	Male	Father	A1

3:4:6 Recruitment: Staff

Once the recruitment of the parents was completed the students who would then form the central group of subjects were also established. From this position I was able to determine which members of staff worked with these young men and which of these members of staff had shown an interest in taking part in this project, all staff were invited to participate (appendix 2 page 236). The staff that finally agreed to take part were then recruited in the same way, with a letter that explained what their involvement was going to entail.

The same process of returning the envelopes was carried out – staff were then provided with a blank return envelope and they returned the letter back to the school reception desk into a box that I had placed there. Out of the twelve members of staff who were initially invited to participate, six staff members agreed to take part for the whole duration of the project. One of the staff participants however requested to carry out their role in the project in private, and that was facilitated.

Below in fig:2 I present a chart which shows the individual characteristics of the staff participants who agreed to take part.

3:4:7 [fig 2: Demographic breakdown of staff participants]

Participants	Gender	Age	Relationship	Socio Economic position	Ethnicity
Staff A	Female	50+	Full time SNP	C2	White UK
Staff B	Female	40+	Full time SNP	C2	Black UK
Staff C	Female	50+	Full time SNP	C2	Black UK
Staff D	Female	50+	Full time SNP	C2	French
Staff E	Female	35+	Full time SNP	C2	Black UK
Staff F	Female	40+	Full time SNP	C2	White UK

Following the successful completion of this recruitment stage I now had two separate groups of participants;

- One staff group comprised of six SNP's [Special Needs professionals - all female staff].
- One parents group comprised of five mothers and one father.
- One group of subjects comprised of five male students from the school.

Twelve participants in all, no male members of staff decided to take part, there were also no teachers and no therapists who agreed to take part.

3:4:8 Optional introductory meetings

Following this initial 'recruitment by letter' phase of stage one of the project, all parents and staff members were invited to attend separate introductory group meetings with the other participants from within their group who had agreed to take part.

At these meetings they were given further information about their involvement in the project, the aims and objectives of the project were explained, and they were once again informed that they could at any point still choose to simply decline to play any further role in the project. At this meeting attendance was voluntary and some participants agreed to participate by returning the acceptance slip on the recruitment letter without attending this meeting. This initial introductory meeting was concerned solely with clarifying what participation in this study may mean for those who had agreed to take part. Parents and staff who felt uncomfortable about attending a large group meeting and/or wished to keep their

involvement confidential but who needed more clarification about exactly what their involvement would entail were offered the option of having a private one to one meeting with the researcher, where they could either accept or decline to take part in the project. Within the 'introductory letter' and at these preliminary 'introduction and information meetings', it was made explicitly clear from the outset that all potential participants had the right to withdraw from this study at any point if they wished to do so, and that all data related to their involvement from the project would be destroyed. Five out of the six staff participants attended this first introductory meeting, which was held in the school at the end of the day. None of the parents attended the meeting arranged for them.

For those staff attending it was reiterated again that their involvement was completely voluntary and that this meeting was being provided for those participants who may wish to hear in greater detail what exactly this study is all about, who may wish to meet up with other participants who were taking part in the project in order to get a feel for what it was all about and what their personal input may be, and to alleviate any initial fears that they may have had around taking part in an interview with the researcher. Before any attendance all participants were personally cautioned about the potential consequences of divulging or discussing any delicate or sensitive information in a group situation, and the importance of confidentiality when sharing personal information in group meetings. These initial meetings were strictly an introductory part of the recruitment process, and did not form part of the data gathering phase of the project.

Both sets of participants were also informed that the interviews and the group meetings would be recorded on tape. And that following the completion of the project all tapes would be destroyed. It was also made clear that during the project all tapes and transcripts of any conversations would be stored securely and would only be accessed by the primary researcher. Sheffield Hallam research ethics protocols in respect of storage of data were followed.

At this early stage in the project the sense that I had from both sets of participants, was that the general feeling within both groups was one of curiosity and of a real sense of willingness to engage in the project in order to explore these issues personally through their own testimonies, in the hope that this might lead to more informed understandings of the

experience of these young men. At the end of this stage in the project it seemed to me that both groups felt relaxed and comfortable in going ahead with the work. Both groups had been defined and all of the participants appeared eager to begin. This was demonstrated by their willingness to start the process with the first one to one interviews. This completed the end of Stage One of the project.

The following section examines the next phase of the research. Here I explicate the methodology used in this study, and describe the individual one to one interviews and the group meetings that formed the primary data collection stage of the project.

3:5 Stage Two: Interviews and Group Meetings

- **Thematic analysis**
- **Adapting Lifeworld**
- **Using Ashworth's 'Fractions'**
- **Interviews with Participants**
- **Group Meetings with participants / post meeting feedback**
- **Completion**

3:5:1 Thematic analysis within Lifeworld

Interviews have become a commonly used qualitative methodology for collecting data (Aronson, 1992). Once the information is gathered, researchers are then faced with the decision of how to analyze the data. There are many ways to analyze informants' talk about their experiences (Mahrer, 1988; Spradley, 1979; Taylor & Bogdan, 1984), and thematic analysis is one such way (Aronson 1994). The first step is to collect the data, in this study this was carried out by taping the interviews, from the transcribed conversations, patterns of experiences can then be listed and categorised, this can come from direct quotes or by paraphrasing common ideas. Within this study, the next step to this thematic analysis was to identify all of the data that related to the fractions. The identification of any recurring patterns within the data are then explored, all of the transcribed data that falls within each of the fractions is identified and placed with the corresponding category. The next step is to combine and catalogue related patterns into themes and sub-themes. Themes are defined as units derived from patterns such as "conversation topics, vocabulary, recurring activities,

meanings, feelings, or folk sayings and proverbs" (Taylor & Bogdan, 1984:131). Themes are identified by "bringing together components or fragments of ideas or experiences, which often are meaningless when viewed alone" (Leininger, 1985:60). Themes that emerge from the participants' stories are then pieced together to form a comprehensive picture of their collective experience. One of the central questions that this study attempts to answer is whether it is possible to access one person's life experience through another's account, and whether this is still legitimately Lifeworld. Through the presentation of the themes that have arisen and which have been captured within the fractions, in combination with an investigation of the participants' stories I would argue that the Lifeworlds of the subjects are discernible and clearly evident, and are clearly represented by the participants.

3:5:2 Adapting Lifeworld

The term Lifeworld refers to our everyday experience as human beings, the meanings that we make of our experience, and how our world is concretely lived. In this study I have adapted Lifeworld as a methodology to enable the addressing of the research questions within this project. Lifeworld points to and places emphasis upon our shared human existence – [literally] what it is to be human, our being in the world, and it is characterised by the qualitative nature of everyday life (Biley and Galvin 2007). Ashworth (2003) suggests that Lifeworld encapsulates the 'key aspects' of being alive which are shared by us all, the parts of the Lifeworld which were not bounded within themselves but which were experienced fluidly with each aspect influencing and being influenced by the other. He described these key aspects as 'fractions' and he argued that within the research process they can act as a way of scaffolding the incoming data and can assist in creating a context for the responses from the participants. The conceptual basis of Lifeworld therefore, is that we exist in a day-to-day world of which we make complex meanings which form the backdrop of our everyday actions and interactions. The phrase itself, Life-world directs attention towards the individual's lived situation as it is and their individual essence, their interaction with those around them within their world – within what constitutes their life.

The methodological approach I have adopted within this study was evaluated as being the most appropriate for addressing the research questions, as it performed two dual functions: One, it provided a starting off point from which to begin framing the examination and

interpretation of the participants' experiences and perceptions through the use of the fractions: Two, it provided access to the 'meaning of experience' for the young men, as interpreted by the participants, and mediated through a supported process of reflection.

The parents and staff who had initially approached me were describing their day to day contact with the young men and the issues they were facing. They had expressed their uncertainty to me directly and were unsure of how they felt about what they were experiencing. They were describing situations and events that they were struggling to understand or find solutions to, and the resultant interactions they were having with the young men who formed this group were confused. My objective therefore was to use Lifeworld in a different way, as an approach that explored experience, but rather than taking a traditional focus on the lived experience of the participants I wanted to use it to focus on and identify the meanings that the participants were making of the lived experience of the five student subjects within the core group. Positioned in this way what became available was a collection of interconnected Lifeworlds which were open for exploration; that of the participants, that of the subjects and through that the Lifeworld that they shared. As far as I know no other researcher to date has explored the value of Lifeworld in trying to understand one person's experience as described by another. Therefore through exploring the viability of this as a discrete methodological approach is one way in which I hope my thesis may contribute to knowledge.

3:5:3 Using the Fractions

Within the research process these fractions can act as a way of scaffolding the incoming data and assist in creating a context for examination and analysis. In each interview I examined different but often interconnected aspects or 'fractions' of both the subjects and the participants lives. In this way each interview had its own specific focus as a starting point. An example of this can be found in [appendix 4 page 241] which examines some of the key aspects of a situation that involve one of the subjects and their primary carers, around the way in which the subject uses their bedroom, and which legitimately crosses over all of the fractions in some form for both subject and participant.

Within this phenomenological approach which positions the personal narratives of the participants within a potentially much more complex interconnected experience that both

participants and subjects feed into and experience together, the different roles of the subjects and participants become available. Clearly it offers up questions around the potential power of the subjective interpretations of the participants and the impact that they can have on the subjects; the impact the subjects have on the ways in which the participants deduce what they feel is happening to the subjects and ultimately how this process of 'response and feedback' has generated the identities of all involved over time.

Through separating typically occurring incidents, events and encounters into distinctive elements these fractions can assist in reminding researchers of the breadth of impact of any experience upon the individual. They can also provide a filter through which experience can be categorised that can act as a way in which to guide the researcher through the analysis as well as the data collection by sorting and organising information into manageable bits (Goulding 1999). Bits that may consist of; words, phrases, expressions captured within the fractions that cluster together to form themes; within these 'bits', 'the researcher clusters the identified meanings into themes that are common across all accounts' (Brooks 2015:642).

I used each of the fractions as a starting point for the one to one interviews and group meetings. I focused on one of the fractions in each meeting and developed questions [appendix 3 page 239] around the specific qualities of each of the fractions. An example of this would be;

Fraction: Identity; in exploring this fraction with participants I would ask questions such as:

- What does the subject do that is specific to them as an individual?
- How does the subject come across to other people?
- How does the subject validate who they are?
- What do they do that is intrinsic to them?
- How does the subject communicate who they are to others?
- Have you noticed any changes in the way that they present themselves to others?

The use of the fractions in this way and the questions posed around what the fraction represented, then acted as part of the overall framework for collection and categorisation from which it was possible to analyse the data. This also acted as a way in which to structure

the interview process, and as a way to examine the individual experience of the student subjects as interpreted by the participants.

I had originally wanted to look at how Lifeworld might enable direct access to the lived experience of the research subjects but this was not deemed by the ethics committee as acceptable. For this reason I have adapted the methodology to represent the lifeworlds of these young men as interpreted by others. There is a call for new ways to enable contributions to research from those who do not access typical forms of communication, therefore I felt frustrated that I was not able to develop these. I am not presenting an interpreted lifeworld as an ideal here but am offering it instead as the best option left open to me. One positive aspect of this was that it enabled me to work with parents and staff in a way that enabled deep discussions around how the subjects appear to experience the world. I hope that this enabled new understandings that will lead to more effective and enabling responses to the behaviour of individuals who typically fall outside of any form of direct involvement in research such as this.

Using Lifeworld adapted in this way - as a means to identify and explore the meanings made by the participants about the experiences of the subjects; which asks the parents and staff to reflect on these experiences and address the question of interpretation and meaning construction, can offer new perspectives around the ways in which people who articulate their worlds differently operate. I now want to examine how this model was carried out in practice during the interviews and group meetings.

3:5:4 Interviews with Participants

One of the central functions of the interview is to obtain open, nuanced, rich descriptions of different aspects of the participant's Lifeworld within which images of specific situations and action sequences can be directly elicited (Marsiglio 2012:2). In this study my aim was to capture interpretations and descriptions around the meanings that the participants had made of the experience of the subjects. This included what they believed the students' behaviour may represent and critically how they have identified the meanings that they themselves had arrived at. Challenging them on how they had decided what to explicate from the available material provided by the subjects, the critical features of a behaviour or response, what they had chosen as having meaning – and asking them for whom, for them or for the subject.

That is, to report back on the potentially hidden stories of the subjects through the telling of their own stories, and to consider where they, acting as potential advocates, were positioned within the lives of the subjects. This duel position, of accessing the meanings of experience for the subjects mediated through the challenged understandings of those around them may have credence as a reliable research tool, when the position of each of the participants is seen as that of both a story teller [telling the story about their own experiences] and an 'advocate' story teller [telling the story of another]. And this approach needs to be tested further in order to measure the effectiveness of this particular method as a means for interpretive enquiry, and as a way by which the researcher can enter into the research participants' worlds (Charmez 2011).

3:5:5 Group Meetings [i]

My decision to use both group meetings and one to one interviews as the primary data collection tools within this study was chosen primarily because it offered the opportunity for the interviewees to provide personal 'qualitative knowledge' expressed in a typical conversational form. This is a standard qualitative method of research. Some of the main advantages of group interviews with participants of any social group are the spontaneity of the discussion (Krueger, 1994), the jogging of each other's memories (Valentine, 1999) and generally the more relaxed and fun atmosphere (Stewart and Shamdasani, 1990). 'Group meetings in general tend to have a substantial degree of flexibility and are in some sense a hybrid with characteristics of a discussion as well as an interview. In this group setting general topics and even specific questions can be presented by the researcher, adding a more focused dimension to the traditional interview format of alternate question and answer, which can be a particular strength within this model' (Robson 2002:283).

Using interviews combined with this approach offered me the opportunity to modify my line of enquiry, follow up on interesting points and responses and investigate underlying motives in a way that the group meetings could not provide:

> 'The interview is focused on particular themes; it is neither strictly
> structured with standard questions, nor entirely 'non-directive'.
> Through open questions the interview focuses on the topic of research.
> It is then up to the subjects [interviewees] to bring forth the dimensions
> they find important by the theme of inquiry. The interviewer leads

the subject towards certain themes, but not to specific opinions about these themes'.   (Kvale 2007:12)

Each participant was offered the opportunity to take part in eight separate group meetings followed up with eight separate one to one interviews. Each of these group meetings focused on one of the fractions and the follow up one to one interviews continued with the exploration of the fraction discussed in the group meetings. I decided to construct the interviews in this way in order to allow first a general discussion around what each of the participants believed the fraction under discussion may represent for the student subject. And, secondly to allow the participant time to respond in a more detailed and individual way in the one to one interview setting.

I adapted the language used by Ashworth (2003) to describe the fractions to make these more accessible for the participants. The diagram in fig: 3 below gives a breakdown of exactly how the fractions were translated into accessible phrases [see overleaf].

3:5:6 [fig 3: Rephrasing the Fractions]

Selfhood (Social identity): How would you describe this person; What is distinctive about the way they represent who they are; How do they come across to others in your opinion; What do they do that is distinctive to them as individuals.
Sociality (Relationships with others): Relationships with family members / significant others in their lives / positive or negative issues related to contact with other people / special relationships.
Embodiment (Physical & Emotional feelings): How feelings are exhibited / What they may do 'physically' if they feel a certain way.
Temporality (Sense of time): Times of the day that are particularly relaxed / times that are particularly problematic; How do they cope with transition when things come to an end or start; how do they use time as a way in which to take and use control.
Spatiality (The spaces occupied): Spaces they enjoy being in / Spaces they prefer to stay away from / How do they cope with transition from one space to another spaces that they are permitted to access/excluded from.
Projects (Activities): Things you do together / activities you have noticed they are interested in / not interested in / solitary activities / private activities.
Discourse (Use of language): The style of communication you share / their own personal communication system / how they may respond to the communication of others / specialised communication with key people.
Mood as atmosphere ('feeling tone' of any situation): Descriptions of changes in mood and reasons why / how do you know when things are ok or not ok / what are the triggers and the responses; how are shifts in mood used by the subjects.

Initially, I had planned for the one to one interviews to run concurrent with the group meetings for each set of participants. In each of the group meetings I would examine with the participants each of the fractions in order to provide a clear format for each of the interview sessions that would follow. In the interviews my aim throughout was to sensitively challenge the current understanding that the participants made of the experience of the student subjects. Drawing the conversation back to ask how the onset of adolescence might have brought about change in the life of the subject. Each participant was asked to decide what

they wanted their interview to focus on following the group meeting, and this was agreed with the researcher at the beginning of the interview – this was their jointly agreed starting point. Used in this way these interviews offered the possibility of modifying and individualising the line of enquiry, in a way that is not always possible in larger group meetings (Robson 2002).

The aim of these one to one interviews was solely to focus on the interpretation and meaning attributed by the participant around each of the specific 'fractions', from the communication, actions and behaviours of the student subject. The exact design for the questions for each interview was formulated over the ten months that this stage lasted. A range of possible questions and possible areas of focus which were examined are provided below. Further examples of the questions can be found in the appendices, see above;

- How do you think your personal understanding of behaviour you have witnessed impacts on the students?

- What do you think these behaviours represent for the students at the centre of this study?

- How do you think others react to these behaviours? And how is that experienced by the student?

- What do you think these behaviours mean to the student?

These questions were all consistent with a focus on understanding what the experience of adolescence means for these students as interpreted by parents and staff. All participants were provided with a timetable of the group meetings listing; time, date, duration of the meeting and which fractions were to be the focus for each meeting.

The interviews with parents were carried out in different ways. To begin with all of the parents were asked where they would prefer to do the interview, four parents said they were happy to come into school or to do the interview at their home. One parent wanted to do the interviews only at school. The parent interviews all took place in the parents' room in the school, a room all of the participants knew well. The interviews always took place after the school day had finished and every precaution was taken to protect the parent's anonymity when in the school. The interviews that took place at the participants' homes were arranged

on an individual basis, between each of the participants and the researcher via telephone and email. Each interview was taped and lasted between thirty to forty five minutes. Throughout all of the interviews the objective was always to explore what the interviewee believed the specific fraction under examination represented for the student subject in as much detail as possible.

The interview phase of this stage lasted ten months and the number of interviews carried out with each participant varied considerably. Some parent participants were able to complete all of the interviews and some only a few, but no parents withdrew from their participation in the project at any point. Some of the staff participants were able to complete most of the interviews, some only a few and one participant dropped out and wished to have no more contact with the project although they were happy to allow the transcriptions already gathered to be used. See fig: 4 below:

3:5:7 [fig 4: Interview attendance]

Participants	Group meeting	Individual interview	total
Parent A	X	2	2
Parent B	X	1	1
Parent C	X	2	2
Parent D	X	1	1
Parent E	X	1	1
Parent F	X	1	1
Staff A	2	1	3
Staff B	3	2	5
Staff C	3	2	5
Staff D	2	1	3
Staff E	3	2	5
Staff F	X	3	3

3:5:8 Group Meetings [ii]

The group meetings were pre-arranged and divided into two separate blocks which spanned four months each, with a month in between when there were no meetings. This was to allow the participants to have a break from the project as I felt that they were giving a considerable amount of their time up and that a break from having to take time out to attend these meetings was warranted. The group meetings were all held in the parent's room in the school and there was a marked difference in attendance and in the way they were used by each set of participants. All of the staff participants attended the majority of the group meetings. The staff group preferred to meet before the school day started as they were already in the building and as a group they agreed that this was a better time to meet. A factor which played a significant role in the way that these meetings developed was that the participants all knew each other well, they were comfortable with each other and the researcher and they were used to talking about the students and the issues we were exploring in the meetings.

The parent participants found the group meetings much more difficult to engage with. This was evidenced by a reluctance to come into school at the end of the day to meet with other parents; requesting to meet on a one to one basis at their homes and not turning up to meetings that had been arranged. It quickly became apparent that these meetings were not going to work in the same way that they were working for the staff participants. For the parents, attendance at these meetings was more difficult as the only times that the group could get together was after school and it was very difficult for some parents to arrange child care or get out of work. Also, although they had met before at parent's forums the parents did not know each other that well and were not working in the place where the project was being conducted. It became clear at an early stage in this study that this feature of the study was not a tenable option for the parents who had agreed to participate. Therefore the group meetings for parents were brought to a close. Data from parents was all collected through one to one interviews.

Written notes were taken at all of the staff group meetings and were used in the following one to one interviews. All of the participants were provided with written feedback from the group meetings and this assisted in re-focussing the one to one interviews around specific issues raised in the larger group meetings.

3:5:9 Feedback and Completion

In order to provide a link between the group meetings and the interviews that followed, all staff participants were provided with a brief summary of the key points that had been discussed in the group meetings. These points were emailed to participants or sent home to them in a sealed envelope. This feedback was on the whole not used by the staff in the way that it had originally been envisaged that it would be, which was as a way in which to develop further discussion and initiate deeper exploration of their role in the study. And when asked if they had looked over the feedback, generally the answer was that most participants had not. My feeling was that they were too busy, and that their involvement in discussion was deemed to be enough for them without the additional burden of reading notes at home.

To draw the project to a close once all of the interviews and group meetings with both separate sets of participants were completed, all involved were offered the opportunity to report back on their involvement in the process. This 'follow up' procedure was in the form of either:-

- The option for parent participants of meeting together as a group to talk openly and discuss how they may have been affected by taking part in the study, what they had taken personally from their own involvement in the project and what impact they believe the project may have had on the way in which they view the experiences of their sons.

- Individual one to one meetings for those participants that preferred to carry this completion process out privately. Here they could discuss their involvement in this project in confidence.

Examples of some of the data collected from these group meetings and individual sessions can be located in the appendices [Appendices 6-10 pages 271-286] and a series of extracts from the transcripts are used in section two of this study in order to provide direct evidence of the way in which the fractions have been used and the way in which meaning and key points within the data were extracted and interpreted.

By the end of stage two of the project there were three separate data sources available: Recorded data collected from the one to one interviews; recorded date collected from the group meetings and notes taken in the group meetings. This concluded stage two of the study.

3:5:10 Summary

The purpose of this chapter has been to provide a detailed description of the way in which an adapted form of Lifeworld was employed as a methodology to access the lived experiences of the research subjects - as interpreted by those around them. I have provided an explanation of the innovative way in which I have used this adapted form of Lifeworld, one which shifts the focus from the Lifeworld of the participant to the meanings that the parents and the staff make of the lived experience of the subjects within the target group. I have described the design for this research project, a research model that while using the voices of those significant others that exist around the subjects, has still maintained these young men's experiences as the central focus of the research process.

In this sense therefore what has been uncovered is an interpretation of these young men's experiences by the people around them. The data suggests that through the rigorous and in depth examination of the personal perceptions and the shared interpretations of the participants, an enhanced sense of the identities of the young men emerged for parents and staff. This process of uncovering and exposure was reported by participants to be a rich and empowering process. In turn the subjects will I hope have benefited from the development for participants of a more empathic understanding of the subjects' behaviours during adolescence.

Lifeworld as a methodology usually expects that people can and will express the story of their own life, however ethical dilemmas as perceived by a regulatory body prevented that within this study. I would argue that Lifeworld, in the adapted form in which it was used in this study, still provided a useful structure that helped to maintain the focus and composition of the enquiry. It was very important to me as a researcher that the humanity and value of the student subjects was recognised throughout this study and that the process of coming to know the impact of adolescence on their Lifeworlds and their individual experiences of

change, sexual expression and personal growth would lead to more enabling engagement for them with others.

Finally, having provided a description of the practical application of this methodology, one that shifts its focus to the way in which one group attributes meaning to the experiences of another a fundamental question arises: Are the ways in which the participants are expressing their own worlds inextricably linked and interconnected with the ways in which they are describing and expressing the worlds of the subjects? The focus of the next chapter is to provide a detailed explanation of the way in which the collected data was coded and categorised and analysed thematically. The analysis of this data used elements taken from the model discussed in this chapter in combination with the themes developed through the use of the fractions in order to provide thematic profiles of the research subjects in the research group.

Chapter 4 Data Analysis

4:1 Introduction

In this chapter I provide an examination of the theoretical, conceptual and practical issues that I faced as the single researcher when analysing the data collected in this study. The previous chapter has provided a description of the methodology used in this project, this chapter will present an account of how the data collected in the research notes, one to one interviews and the group interviews was analysed and themes identified. Kvale (2007:11) states that, 'the interview is a uniquely sensitive and powerful method for capturing the experiences and lived meanings of a subjects' everyday world' – and that it involves a specific approach and technique. The method and procedure for carrying out the interpretation of the interview transcripts collected during this study and the final form in which the data itself was presented are complex, and have revealed a series of issues around the way in which my analysis of the data proceeded, which I explore throughout this chapter. In this study a number of methods of analysing unstructured textual data are identified, ranging from a grounded theory approach such as the one advocated by (Glaser and Strauss 1967) to a more impressionistic method of presenting research findings (Jones 1985). This impressionistic research approach is guided by the theoretical orientation that individuals construct their own personal meanings about things rather than reflecting social meanings. Social meanings are said to be impersonal, reified, monolithic, and static, whereas individuals are said to be active and to never merely receive social meanings. Instead, individuals always transform social meanings into personal significations (Ratner 2002). This study has set out to explore this area of personal significance and individual meaning, for both the subjects and for the participants.

Qualitative research methods have been widely recommended as a way of collecting data about people's subjective experiences, their views and their perceptions (Munhall & Oiler 1986; Somer & Somer 1991; Morse 1991). The approach that is described in this study proposed a systematic means of analysing a mass of qualitative data by extricating information from the transcriptions and assigning it into the most relevant of the eight of Ashworth's fractions of the lifeworld. Primarily, this approach adopted a mode of analysis utilised within phenomenological research that provides a category system and a way of

grouping together ideas, expressions and perceptions that capture related elements of experience of a similar sort. In order to demonstrate how this examination of the data was carried out I have used a selection of examples from different stages of the analysis. This will illustrate how I have approached the decoding, interpretation and final extraction of the key points, meanings and themes through my analysis of the interview transcriptions.

The purpose of this chapter is therefore to:

- Provide a clear explanation of the way in which meanings within the data were identified and interpreted.
- Provide a clarification of how key points, units of meaning and themes were identified within the transcriptions.

4:2 Meaning Units

Dey (2005:16) states that 'Data are not 'out there' waiting collection, like so many rubbish bags on the pavement. For a start, they have to be noticed by the researcher, and treated as data for the purposes of his or her research'. One of the first steps in the analysis of the data in this study was to identify what 'units' of meaning within the transcripts looked like. A number of researchers have proposed clear definitions about exactly how to define what a meaning unit is when sorting through research data. A meaning unit, that is, the constellation of words or statements that relate to the same central meaning, has been referred to as a content unit or a coding unit (Baxter, 1991), an idea unit (Kovach, 1991), a textual unit (Krippendorff, 1980), a keyword and phrase (Lichstein and Young, 1996), a unit of analysis (Downe-Wamboldt, 1992), and a theme (Polit and Hungler, 1991). Graneheim & Lundman (2004) have described a meaning unit as the constellation of words or statements that relate to the same central meaning. Elliott & Timulak (2005:153) use this definition suggesting that 'meaning units are usually parts of the data that even if standing out of the context, would still be able to communicate sufficient information to provide a piece of meaning to the reader'. Graneheim & Lundman (2004:106) see meaning units as 'words, sentences or paragraphs containing aspects related to each other through their content and context'. These units then can be represented as the coherent and distinct vehicle within which the meanings lay embedded within the transcripts. They can be composed of any number of words and even one word may constitute a meaning unit. Several sentences may also

constitute a unit. A meaning unit may contain a complex idea; it simply must be coherent and distinctive from other ideas. The meaning unit must preserve the psychological integrity of the idea being expressed and it must neither fragment the idea into meaningless, truncated segments nor confuse it with other ideas that express different themes (Ratner 2002).

The approach that is described in this study offers a systematic method of analysing textual data, by breaking the text down into meaning units, then using a system of categorisation [separation of the data into each of the eight fractions] and from this grouping together data of a similar sort, in order to arrive at core and sub themes. In these respects, the approach is similar to the process known as phenomenological analysis (Giorgi 1985; Kvale 1983) and has much in common with content analysis, a general term for a number of different strategies used to analyse text (Powers & Knapp, 2006). This is a systematic coding and categorizing approach used for exploring large amounts of textual information unobtrusively to determine trends and patterns of words used, their frequency, their relationships, and the structures and discourses of communication (Mayring, 2001; Pope et al., 2006; Gbrich, 2007). This type of analysis has been described as a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding (Berelson, 1952; GAO, 1996; Krippendorff, 1980; and Weber, 1990). Holsti (1969:14) offers a broader definition of content analysis as, 'any technique for making inferences by objectively and systematically identifying specified characteristics of messages'. This study has within it certain characteristics of a form of content analysis in that it is reductive in its approach and that it searches for trends, patterns and ultimately themes within the data. Yet it approaches the information within the transcripts in a different way, through the means in which the fractions have been employed as a way to categorise and sort the data, allowing the themes within the data to naturally emerge from each of the fractions and across the fractions. In this study the fractions have already been labelled, and they act as headings for each category. Therefore the units of meaning as they are located in the data were placed in each fraction or across multiple fractions. From this position there is the necessary process of abstraction, whereby the units of meaning are gathered within a fraction to form them into a theme. In this study this process of abstraction entailed both the removal of certain characteristics, combined with the inclusion of others, which led to the emergence of the main themes available within the data collected across the fractions.

As the researcher I accept that the way in which each of the core themes has been arrived at is likely to be one potential abstraction of a number of possibilities. It has been argued that the researcher, who has a broader understanding of the context influencing the stories of research participants may well develop a wider understanding of what is going on, in addition to the understanding that she or he may share with those participating in the research (Downe-Wamboldt 1992). However through my analysis of the transcripts I was able to sense a pattern or occurrence taking place. This '"sensing" of a pattern of something significant occurring' (Boyatzis 1998:4) led to my observation that something important or notable was taking place within the data, something which provided a link between a new or emergent pattern which culminated in the development of the core and sub themes.

4:3 Analysing the data

The main body of data for this study was collected from eighteen interviews (lasting between 30 minutes to one hour) which were taped and transcribed. This generated in excess of 50 thousand words. Goulding (1999:7) describes the process of analysing data, within the phenomenological tradition as 'a process of scrutinising the text narrative structures or meaning ''units'' which describe the central aspects of the experience'. The approach I adopted in coding the data was to analyse the transcripts line by line, this approach offered me the opportunity to see how the research participants' actions and statements could teach me in a very short period of time about the worlds of their subjects, albeit sometimes in ways that they themselves did not anticipate. Charmez (2006:51) suggests that studying the available data in this way can often spark new ideas for the researcher to pursue. This was regulated to a great extent by the way in which the fractions helped to categorise the data. However the process by which I made a decision about what a meaning unit actually was involved a series of separate processes. First, was the recurrence of a key word, phrase or expression that was continually linked to a situation, event or experience that repeatedly presented itself within the data. Second, was the way in which the interviewee would base much of what they were describing around the same themes or would describe the same situation or event occurring across many different scenarios. Third, the overlapping nature of these recurring meanings across some or in some cases all of the fractions.

The interview transcripts were examined individually and colour coded as to which fractions the text related closest to. This led to three data sets; one which represented all of the data taken from the transcripts from the staff meetings, one which represented all of the data taken from the transcripts of the individual one to one interviews; and one which represented the data collected within the additional research notes. These were then divided into three separate sets of transcriptions: Parents' one to one interviews, staff one to one interviews and staff group meeting interviews. From the outset all of the parent participants made it clear that they would not be attending any group meetings therefore this data set was not available.

Each set of transcriptions was then examined for emerging key points and themes within the data. Where repetitive responses or key words within the text were identified between transcripts they were highlighted and examined as potentially developing commonalities or as core themes.

4:4 Themes

It has been suggested that every analysis requires a context within which the available texts are examined, and that the researcher must construct a world in which the texts make sense, allowing them to answer research questions (Krippendorff 2004). Thematic analysis as an independent qualitative descriptive approach is mainly described as "a method for identifying, analysing and reporting patterns (themes) within the data" that is available (Braun & Clarke, 2006:79). At the heart of any qualitative data analysis is the task of discovering themes and in this study that has entailed the analysis of a set of written texts [the transcripts]. Looking for themes in written material typically involves examining texts and marking them up with different coloured pens. Sandelowski (1995:373) observed that analysis of texts begins with proofreading the material and simply underlining key phrases basically 'because they make some as yet inchoate sense'. Within this study 'themes' are defined as particular subjects or experiences that are discussed often or repeatedly within the transcripts by the research participants (Merriam-Webster 2014). The researchers Ryan & Bernard (2003:86) have suggested that 'a thematic analysis of any texts involves several separate tasks: first is the discovery of the themes and sub-themes. Second is a filtering of the themes down to a manageable few (i.e., deciding which themes are important). Third is the

building of hierarchies of themes and fourth is linking these themes into theoretical models'. Opler (1945) established three principles for thematic analysis. First, he observed that themes are only visible (and thus discoverable) through the manifestation of certain expressions within the data. Second, he noted that some expressions of a theme are obvious and culturally agreed on, while others are subtler, symbolic, and even idiosyncratic. And third he observed that cultural systems comprise sets of interrelated themes. And 'the importance of any theme is related to how often it appears, how pervasive it is across different types of cultural ideas and practices, the degree to which the number, force, and the variety of a theme's expression is controlled by specific contexts' (Ryan & Bernard 2003:87). Seen in this way themes can therefore be seen as clear representations of a collective or shared event experienced by individuals, the evidence of which may lie across multiple contexts.

Within Lifeworld, any themes can only become available within the data once the researcher has removed their own bias from the analysis. It has been suggested that in order to identify the Lifeworlds of others this type of existential phenomenology requires that the researcher, must first suspend or 'bracket' any notion of reality in order to focus upon elucidating the conscious experience of the research participant (Harvey, MacDonald, and Hill 2000; Ashworth 2003a cited Hodge 2008). This process of bracketing therefore requires the researcher to step away from the data, allowing the material derived from the interviews to speak for itself. However, in this study I was tasked to identify the meanings within the data which on occasion were naturally located into themes that were common across all of the accounts provided by the participants. Lifeworld's relationship to themes is therefore double edged, it focuses on the richness of personal narratives uncluttered with any form of interpretation while allowing for the emergence of themes to arise, if they do so naturally, that is as part of the ongoing development of the data. This presented me with the task of both allowing the data to retain its personal quality within the transcripts, whilst exploring the data for connections and themes.

The concluding phase of the analysis of the four data sets culminated with the production of the final meaning statements, commonalities and from this, themes and sub-themes.

4:5 [fig 5: Diagram of the separate stages of data analysis]

Stage One

- Transcripts of the recordings were made of all of the nineteen one to one interviews and eight group meetings. This stage also included my meeting notes

Stage Two

- The transcripts were analysed for meanings of experience and elements of the data [the words, phrases and expressions used by the participants] were assigned to each of the eight separate 'fractions'.

Stage Three

- The eight Lifeworld fractions were then examined separately for key phrases, words, expressions that would indicate towards a key point or meaningful event occurring in order to:

  [1] Identify the ways in which the onset of 'adolescence' had impacted on the young men as reported by the parents and staff.

  [2]Identify commonalities [themes] and differences in how parents and staff experience and understand the developing lifeworlds of these students in the same way.

Stage four

- The identification of 'themes' and 'sub themes' taken directly from the data collated within and across the fractions to identify the structure of this experience [adolescence / sexual development] for the parents, staff and young men.

Stage Five

- Dominant themes and sub-themes were established following the categorisation of the data within the transcripts across all of the eight fractions.

4:6 Positioning Lifeworld within the data

Ensuring that all of the stories of those involved in this study were available within the data was a central aim throughout this phase of the study. It has been suggested that the quality of any phenomenological study can be judged in its relative power to draw the reader into the researcher's discoveries, allowing the reader to see the worlds of others in new and deeper ways (Finlay 2009). What are being presented within this research are the stories of a group of people who have been willing to share their interpretations of the experiences of others. However, importantly what is also identifiable within the unfolding narratives of the participants is the presence of the young men who have acted as the research subjects for this study.

Using the fractions both as separate categories but also considering them as occasionally interlinked (Ashworth, 2003), has offered an opportunity to organise the data to see the hidden dimensions of the young men [the subjects] themselves as well as the hidden dimensions of the significant others in their lives [the participants]. From this, what has become available are the Lifeworlds of the subjects as interpreted by the people around them.

For the subjects these hidden dimensions are the indicators of some of the ways in which they have validated their identities, forms of personal representation that can easily remain hidden within: behaviours that may present challenge, communication systems that are highly individualised and ways of being that are difficult to decode. For the participants these hidden dimensions have emerged from their reflections on how they have interpreted the responses and behaviours of the subjects and their concurrent responses. These dimensions became revealed over the duration of the first phase of the study as the participants were asked to explore each fraction in the interviews, they emerged during the analysis of the data in the form of themes and sub-themes found within the transcripts and they became apparent through my own interpretation of the themes.

This has provided an opportunity to view this potential relationship between both groups as a structural whole that is shared by both, while acknowledging that it is being experienced in individual and very particular ways. The experience of disability may therefore represent a state where by the Lifeworlds of the young men within this study and their parents and the

people that support them, becomes shared at a deeper level than might otherwise have been expected. Viewed in this way, the shared Lifeworld experience for both subjects and participants becomes a jointly accessible domain that they are both recipients of and contributors to.

The task of the data analysis was therefore to reveal the deeper underlying and intentional meanings that are being born, first in the relationship between subject and phenomenon, but also in the inter-subjective relationships (Dhalberg 2006). It also attempts to understand and explicate the meaning of another's experience, through adopting a thematic reinterpretation of the fractions of the Lifeworld that gains access in some way to the meanings of experience for the research subjects as mediated through the challenged understandings of those around them. The following section explains how this was carried out and how the data was assigned to each of the eight fractions.

4:7 Assigning data to the fractions

Two issues I faced before approaching any type of analysis of the data I had collected were, how am I going to define what a key point is within the data and how will I recognise key points when I am analysing the transcribed interviews? Kvale (1996:184) states that ''to analyse means to separate something into parts or elements''. Therefore in order to assist in carrying this out I began by providing clear definitions for each of the fractions that I was going to separate the data into. The fractions proposed within Lifeworld when used in this way provide a really useful framework of captured experience (Hodge 2007), from which to begin the deeper investigation into the meaning within the texts. Providing clear definitions for each of the eight fractions was required to provide a higher degree of clarity when sorting the data. The definitions for each of the eight fractions have already been provided in the previous chapter, however where it is required further clarification and additional re-defining of the fractions is provided in each of the separate chapters related to the four main themes that emerged from this study, in section two.

Below is a colour coded extract from one of the transcripts to illustrate how the process of identifying key points within the data was carried out. This style of research and analysis has called for what Strauss and Corbin (1998) describe as creativity from the researcher, a certain level of closeness to the participants and an ability to interpret situations and statements.

Each transcript was examined and coded in this way with the phrases, words, sentences or expressions presented by the participant highlighted in the colour that represented their relationship to the fraction that I felt they most clearly fell within.

4:8 [fig 6: Example of a colour coded extract]

Colour coding used for each fraction	
1. Selfhood	5. Spatiality
2. Relationships	6. Projects
3. Embodiment	7. Discourse
4. Temporality	8. Mood as Atmosphere / Tone

Interview Extract [1]

T: **So when he was ten he started to develop an understanding of what was ok and where it was appropriate to touch himself?.**

S: Yeah, both him and his brother started to work out and where was ok, and not ok and for both of them now their bedroom is their private sanctuary, but for [A] if he doesn't have to go anywhere – then he likes to be in that bedroom for half a day – and then when he emerges its usually when he wants some food, and he kind of gets up and comes upstairs in his own time, he's not really much of a morning person – so I think that space down there – that's when he has that time for himself – where he can masturbate or whatever he does, I don't know, erm...and he knows that its fine because that's his area – it's not the kind of – you know I wouldn't keep bursting into the room every 10 minutes, I'd just leave the boys to get on with it down there and then they'd come up unless it was a college morning and then obviously then I have to go and get them out of bed and get them ready...I mean he never jumps up out of bed, you know [A]...you've got to coax him, I mean he knows he's got to get up – but you've got to give him time and it might take 10 minutes before he actually gets out of bed but he will do it eventually. But that room is really their space really, and that's their private space – that is the place where if there is anything physical or sexual going on for [A] it's in his bedroom and occasionally I've had to go into his room and he has the covers up to here [his neck] and his hands are going [moving up and down] under the duvet. So I just pretend that I haven't seen him, I just get what I need and I leave as quickly as possible......

By highlighting the separate qualities of the data in this way, the experiences of this participant have been categorised around the fractions of the Lifeworld that they most directly bear the closest relationships to. However, during the analysis of the transcripts this

has on occasion presented a situation where there have been dual meanings arising from the data which fit comfortably across a number of different fractions.

4:9 Exploring Dual meanings

There have been occasions during the coding of the transcripts when certain phrases or expressions have overlapped, with the same experience falling within more than one fraction. This is why the term 'fraction' rather than 'category' is used to represent that the Lifeworld cannot be viewed as being divisible into distinct parts. Ashworth (2003:3) states that 'these fractions are not conceptually or analytically separable measurement-items in the usual sense, for they are not mutually exclusive – the meaning of one is intrinsically affected by the meaning of the others'. The term 'fraction' is used to indicate the way in which each of these seven parts of the Lifeworld [although in this study I use eight including the additional fraction of 'Mood and atmosphere' as proposed by Ashworth 2003] are to be taken as 'bits' of a Lifeworld. An example of this dual or multiple meaning can be found in this phrase below:

'......I mean he never jumps up out of bed, you know Arran...you've got to coax him, I mean he knows he's got to get up – but you've got to give him time and it might take ten minutes before he actually gets out of bed but he will do it eventually.....'

I have categorised this passage within the fraction 'Temporality', as I have interpreted it as relating directly to:

- A clear time of the day [morning].
- The way in which Arran appears to use this time of the day.
- The importance that this time of the day has for Arran which is clear within the passage.

This passage also relates to certain features that can be categorised within the 'Selfhood' Fraction, as it also relates to:

- An opportunity for Arran to exert his will / identity ['not getting up'].
- An illustration of a certain feature of his personality, his mother goes on to talk about this and the way he uses the privacy of his room.
- An indication of his attempt at controlling a certain area of his experience [getting up].

However it could also just as easily have been categorised within the 'Spatiality' Fraction, as it also relates to:

- Control over a space
- The importance of this space in contrast to what it had previously represented during childhood.
- How this space has been chosen and others have not.

When these dual meanings have occurred I have made every effort to identify as many meanings from within the data as is possible. In addition to this I have provided evidence taken directly from the transcript to support the decision to place the data in the fractions they have been categorised under.

4:10 Identifying key points from within the data

- **Identifying and extracting key points from the data**
- **Interpretation and meaning statements**

Following the grouping of the language available in each of the transcripts into the eight separate fractions, each fraction was then analysed again in order to locate key points, recurring experiences and repetitive behaviours that have been reported by the participants. This is a process that utilises the construction of analytic codes [such as the identification of key phrases or words already mentioned] and categories from the available data – not, from any type of preconceived logically deduced hypotheses (Charmaz 2011:5).

I will now examine the way in which key points are identified from within the data and how these key points are expressed and interpreted.

Key Points

In this study I have used the fractions as a means to code the data and then assign it into categories [the fractions]. This means naming segments of the transcripts with a label that simultaneously categorizes, summarises and accounts for each piece of data (Charmaz 2006:43). Within each category there will be key points embedded within the data, these key points are defined in this study as ''the salient, common or significant themes that encapsulate a set of ideas contained in numerous text segments'' (Attride-Sterling 2001:392).

The separate characteristics of these key points may exist in various forms in the transcripts; different words to describe the same experience, family-centric phrases or subtle nuanced ways of speaking about things that the participants are describing in the interviews. It was my task to identify these characteristics and to provide the evidence that would support their interpretation, an example of this process is provided below.

In this extract taken from the 'Relationship' fraction, the interviewee has been describing how her son [Arran] and her husband cope with the Saturday morning swimming session, how they deal with the cubicles and how her husband still dries his son in the cubicle that they both share. In this extract the interviewee commented that she also dries her son when he has showered and that she felt Arran did not feel any embarrassment about this. She also comments on how the family generally deal with any nudity in the house and with each other.

4:11 [fig:7 Locating key points]

Interview Extract [2]
T: So do you feel that Arran would show embarrassment around his sisters? S: No I don't think so, but then again they wouldn't really dry him after a shower, but to be honest we're not the kind of household that would make a big deal about that kind of thing. If anything we would just treat it with humour, you know 'nudity' and that sort of thing. **T: So would you say that humour is a way of dispelling any friction or tension, would you say that's the case...** S: Yes, definitely, even, say if he was doing something inappropriate, my husband would probably just say something funny to stop him from playing with himself, he wouldn't get really stern, he'd use a kind of jokey manly banter, and Arran would get the gist of it and he would laugh and then he'd be in on the joke. Yeah – I think we deal with a lot of things with humour, it's an effective way to deal with potentially embarrassing situations and I think also you end up being on the same level as somebody with learning difficulties; you end up on a kind of common ground with humour. It can be quite subtle, it may not even involve words, and sometimes it can be a look or a gesture or something like that. Arran's

> definitely on our level with a sense of humour. So that's a good way – and I think. Yeah, and I think with the sex thing it's quite good to deal with it in a humorous way.

In this extract the 'key point' that I have identified is the use of 'humour' within the family, and the way in which they use it to deal with certain situations that may impact on Arran's developing sexual identity. The use of humour used in the way that it is described by the interviewee may potentially be seen as an indicator of the types of 'relationships' that exist within Arran's life, and the way in which the family relate with each other in supporting him and his sexual development. This family clearly feels that 'humour' reduces the tensions that exist around bodies and their functions. In examining this extract there is sufficient confirmation, evidenced through the repeated use of humour as a response to potentially difficult situations, to view the family's way of relating with each other and with their son, as in some way supportive and understanding as can be clearly seen in these comments;

... Arran's definitely on our level with a sense of humour'...

...'we use humour all the time every day to dispel any unnecessary tensions'...

...'I think we deal with a lot of things with humour, it's an effective way to deal with potentially embarrassing situations'...

The impact on Arran through the use and application of humour appears to have been a positive experience for him. This has been developed and maintained over time through his family's acceptance and the embracing of his attempts at physical self exploration as part of what they feel is his sexual development. And although he may still touch himself in a way that may be described as inappropriate he will not receive a negative reaction, as the relationships that currently exist within the family are supportive, and are able to accommodate Arran's exploration of himself and his sexuality.

Therefore to summarise, the Key Point is 'the use of humour' and its direct impact on Arran:

- The tensions of adolescence are reduced through the use of humour.
- Arran's mother feels that her son is less stressed, less anxious and more relaxed because of the way in which humour is used within the family to support him, and that

humour has acted as a way to develop positive relationships between him and his family. Humour may also defuse tensions in relationships, prevents barriers from forming, reduce personal stress, act as a family bond, demonstrate acceptance and give pleasure.

- She feels that her son is developing a positive self image because of this.

- Arran is not exhibiting any stress behaviours that the family have previously reported on at home [biting hands / hitting his head / acute anxiety behaviours].

- A reduction of behaviours that may be described as presenting challenge.

- This has also meant that Arran has access to a range of relationships at home all of which are supportive of his [potentially] sexual development.

- Arran is experiencing the impact of this approach as positive and there is observable positive feedback from him, a reduction in self injurious behaviour and he is smiling, laughing and appears calm, which are signs that his mother interprets as indications that Arran is having a positive experience.

This example shows how the transcript is first deconstructed around the eight fractions in order to capture the impact of the identified phenomena across all elements of the Lifeworld, in this extract the fraction that this rests in is 'relationships'. In this example the 'key point' is the way in which humour is utilised by the family. The interpretation of this extract has identified the way in which this family has developed their own strategies to manage issues arising from Arran's new found exploration of his body and what that may represent for him, such as nudity, physical intimacy and touching.

4:12 Interpretation and Meaning units

I have described the way in which the transcribed data is categorised into different parts ['fractions' of the Lifeworld], I have described how this data is then re-examined for key information [key points], and I have looked at the way in which these key points are interpreted in terms of their impact on the research subjects. I now want to re-explore the process by which the interpretations of the key points are decoded into separate 'meaning statements', a process which formed the final phase of the data analysis and provided the definitive final data set.

As has already been discussed in this chapter a unit of meaning as it is understood within this study is a discrete phrase, sentence or series of sentences which conveys one idea or one set of related perceptions (Mostyn 1985). Each meaning unit should stand on its own but, within this study, it is likely to be related more or less, to the units that precede it and the one that follows it (Burnard 1994). After all, these meanings were embedded in the stories of the interviewees, their collective impact was retrieved and examined over a series of discussions with each of the research participants.

Throughout this study, accessing the 'meanings' of experience for the research subjects has been carried out through a process of mediation, through challenging the understandings of those around them, rather than taking a traditional focus on the lived experiences of the research participants. Throughout the study I have wanted instead to use this 'focus' to identify the 'meanings' that the participants were making of the lived experience of the research subjects. From this position, I wanted then for us to consider what the implications of these 'meanings' might be and what direct impact they may have on the Lifeworlds of the research subjects. I will now explore the way in which these 'meaning units' are extrapolated and how their legitimacy as an end product is arrived at.

The first step in this process was to identify the development of the 'meaning units' within the data. The fractions assisted in this process as they act as way of filtering the data into separate thematic markers, which assisted with the management of the vast amount of transcription that this study demanded. [See fig: 8 overleaf a diagram illustrating how 'meaning units' were located within the text].

4:13 [fig 8: Locating the 'Meaning unit']

- Using the data within each fraction the text is examined for key points that have arisen during the interviews. The key points are viewed as indicators of significant events, experiences or responses that are clearly discernible within the text. Evidence is gathered in the form of language directly related to these recurrent themes.

- Following this interpretation stage of the analysis the final 'meaning unit' is deduced. This will focus on the assumed 'meaning' that the participants are making of the lived experience of the research subjects

- These meaning statements are then interpreted and their impact summarised and from this position main themes and sub themes are located

In the example below I trace the formation of the 'meaning unit' from its origins within the text, through the identification of key points taken from the data through the interpretation to the final formulated data set. The focus throughout is located around the identification of:

- The impacts of adolescence on the Lifeworlds of the young men as identified by the parents and staff.
- Any differences in how parents and staff understand and respond to this impact.
- The taking of the parents and staff on a phenomenological journey by asking them to refocus their thoughts from the perspective of the young men, and to examine how that has impacted upon the subjects.

4:14 [fig 9: Identifying and extracting meaning]

Interview extract [3]
M: At home, we've always been very, perhaps to relaxed about it [nudity], we see it as a natural thing, he's been around in the morning when I've been getting ready for work, using the toilet and so on.
T: How do you think he deals with this relaxed attitude now that he is adolescent?
M: Well there's been a change I suppose, we have to be more careful and that's created tensions for us and for him, things are different now, and the way that Gerry comes and goes in and out of the rooms, it's different. That's created problems for sure.
T: what type of problems?
M: Well we can't be like we were before, he's older now and I miss that closeness and relaxed way of being with him, and I think he's picked up on that. Sometimes he reacts to that, and then I panic and it's a spiral. A nightmare. Now we lock the doors and this has definitely had an impact on Gerry, his biting has started up again and his spitting

In this example the analysis begins with the content of the text assigned into the different fractions that it best relates to, in this instance they are: relationships, selfhood, spatiality, time, projects and mood/tone. From this position the next stage is the location of the key points, here it appears to be 'the changes in the access to rooms' which has occurred as Gerry has entered puberty. In support of this interpretation evidence from the text is gathered:

'...the way that Gerry comes and goes in and out of the rooms, it's different. That's created problems...' and '...now we lock the doors and this has definitely had an impact on Gerry, his biting has started up again and his spitting...'

These statements are then summarised. From this extract it is clear that Gerry is struggling with the changes that are taking place at home. Where previously he had free access to roam from room to room, now things have altered. The private space in the house now represents something quite different for both parents and for Gerry and this has led to a raised level of tension. The parents now lock their doors and the spatial freedom and physical closeness that had been a feature of Gerry's world before has stopped. Gerry is communicating his emotional reaction to this by biting and spitting. The assumed 'meaning' that his parents are

making of the way in which Gerry is processing the current situation is: For Gerry adolescence has led to changes in how physical spaces are managed and accessed. Locks and restricted areas have entered Gerry's life. These changes have created tensions that act as locks to emotional closeness.

- His quality of life is reduced by the shift into adolescence.

- He now experiences people acting differently to him.

- He is now separated from people.

- His shift into adolescence has led to tension.

The concurrent response that Gerry is presenting as a reaction to the way in which this assumption is being acted on is:

- Presenting with self injurious behaviours.

- Presenting challenging behaviours that his parents are struggling to cope with.

These final assertions of 'meaning' represent the final key points taken from the examination of the transcribed text. Each transcript is examined in this way, with the final phase being the examination of the way in which the meaning made by the research participants [staff and parents] directly impacts on the research subjects and ultimately the bearing they have towards the research questions.

4:15 Summary

The role of this chapter has been to describe and illustrate the process of data analysis employed in this study. This has taken the form of a step by step breakdown of the way in which the words and phrases within the transcripts were first assigned to each of the different fractions, followed by a re-assessment of the data content that had accumulated in and across each of the fractions. From this position, key points within the data were located and then following a process of abstraction and interpretation based on evidence drawn directly from the available data the final meaning statements were arrived at. This data analysis chapter has explicated the process by which the data has set out to explore whether parents and staff both experience the act of understanding the developing sexuality of the subjects in the same way, and whether it is possible to recognise essential features to identify the structure of the experience.

I have provided an explanation of the ways in which meanings within the data I had collected were identified and interpreted and I have clarified how 'key points' and 'units of meaning' were recognised and distinguished from each other. I accounted for the way in which I have used an adapted form of Lifeworld combined with a thematic analysis within the study and articulated how Lifeworld was not being used as a discreet methodology but as a means through which to assist in the organisation of the data that I had amassed. In this study I have used the eight fractions of the Lifeworld as described by (Ashworth 2003) as a way to group the data extracted from the transcriptions. I provided a description of the coding that was to be used in this study, and described how it would work as a way to order and to extricate key themes, through the identification of recurring phrases or words, and repetitive responses. I described how I explored the responses, which appeared to suggest that significant events had occurred, both individually for each of the participants, but also collectively within both of the separate groups [parents and staff].

In this study accessing the meanings of experience for the research subjects has been mediated through challenging the understandings of those around them and the descriptions they provided of their interpretations. Kerlinger (1970) defined this initial coding stage as the critical phase of any research study, where by the translation of question responses and respondent information into specific categories for the purpose of analysis takes place. During the data analysis phase of this study it became clear that the notion that each of the fractions was mutually exclusive and that each fraction would hold discreet data only relevant to its heading was untenable. What had naturally occurred during this process of analysing the data was that in practice the fractions had acted as separate parts of a coherent whole with overlapping interpenetrating meanings and themes (Ashworth 2003). What had become clear was that there was, to some degree, a sense of interconnectivity within the fractions and that Lifeworld adapted in the way in which it was for this study had provided evidence of this situation. This chapter draws section one of this study to a close, in section two I present an exploration of the main themes and sub themes that have emerged from the data and examine the interpretations I have arrived at and the potential impact of my findings.

Section Two: Findings

Chapter 5 Control

5:1 Introduction

Following the grouping of the data into the relevant fractions, themes became identifiable and were provided with titles; some of these titles related directly to the language in the transcripts as some of the phrases used by the participants captured the essence of the themes that were beginning to emerge from the descriptions reported by the interviewees. The themes that have been identified are: Control, Relationships, Communication, and Expressions of Identity. Within these four core themes it became apparent that further sub-themes were identifiable as certain features of each theme required more specific enquiry. Each emerging theme as it arose across the relevant fractions is used here as a separate chapter within this central section of this study, in which the findings are examined. Within this section I present an exploration of the core themes and sub themes extricated from the data, which are then situated within the current literature to show how the findings both inform and are informed by what is already known. This is combined with an analysis of what the data appears to represent for both the subjects and the participants and an explication of how this may relate to the experience of sexual development and identity formation for this group of young men, as it is interpreted by the people who care for them and who work with them.

In order to arrive at these core and sub themes I have analysed the data by colour coding the transcripts and separating the coded data into each of the eight fractions [see Chapter Three], through organising the data in this way a series of methodological issues became apparent that I had not previously considered. One of the first things that became clear was that some of the fractions were far more relevant to the experiences of some of the subjects and participants than others. For example the fraction 'Selfhood', which related to the subjects' sense of social identity, and how each of the participants believed the subjects perceived themselves as coming across to others, was an extremely complex topic for the participants to examine. And although a significant amount of data was collected within this fraction, the ways in which the subjects were believed by the participants to have represented their identities were often difficult to explicate from the data. The reasons for this complexity lay

within some of the participants' personal understandings and beliefs around the ways in which they believed the subjects were able to identify themselves as separate personalities that could be perceived and known by others. Some of the difficulties that the participants had encountered around locating the intentional projection of identity from the subjects, outwards towards the people around them is something that required further examination, and will be explored later on in this study [see Chapter Eight]. Whereas it became clear at an early stage during the analysis of the data, that the three fractions 'Spatiality', 'Sociality' and 'Temporality' were key features of the lives of the subjects and ones that the participants had experienced in some depth and could report back on with a high degree of assurance. This led to these three fractions becoming filled with coded extracts and provided scope for the identification of a range of different themes which on occasion bridged all three fractions.

5:2 Control

An example of this can be found in the theme labelled control which had within it three distinct sub-themes, all of which warranted specific attention, as they had within them subtle differences that required reporting on separately. There were clear themes emerging from within certain fractions in this way and occasionally across fractions, that is: the same themes were identifiable in two or more fractions but in markedly different forms, as can be seen in these three examples below which centre around this idea of 'control' and how it was experienced by one of the subjects;

Example One: Fraction: 'Spatiality' / Theme: 'Control' – 'He just didn't like anyone coming into his bed room, that was totally his space and we just had to respect that' [Transcript 2: Parent E / Arran].

In this example there is evidence of the subject's attempt to control the space he is in by denying access to his bedroom.

Example Two: Fractions: 'Temporality' and 'Spatiality' / Theme: 'Control' – 'When the [school] bus turned up we'd just have to wait until he was ready to leave his room, and he would only come out when he was ready' [Transcript 2: Parent E / Arran].

Here, there is evidence of the subject's attempt to control the length of time that he spends in this space [his room] before boarding the school bus.

Example Three: Fractions: 'Temporality', 'Spatiality' and 'Sociality' / Theme: 'Control' – 'sometimes in the morning, him and his brother just stay in that room doing whatever they are doing, they're so tight with each other, we aren't really allowed in and sometimes we have to let the [school] bus go, cos neither of them will come out' [Transcript 2: Parent E / Arran].

Here, there is evidence of the subject extending the amount of time in the bedroom, refusing to leave this room to board the bus, linked with the impact of the close connection that he has with his brother. In these extracts I would contend that control is being utilised by the subject effectively in order to achieve the outcome that he appears to require from this daily ritual.

As it is used in the context of this study this experience of 'control' for people positioned on the autism spectrum is defined as: a way of bringing safety and sensory comfort to an unpredictable, unsafe, uncomfortable world (Simone 2016). Within this very specific definition control is seen as inextricably linked with the reclaiming of power or personal influence over outcomes that may take place in the immediate environment. It has been suggested that for some people on the autism spectrum who experience anxiety, may in extreme cases, try to establish control over their environments; they may turn to trying to "control" their bodies – and when there is nothing else to control, then there is always control over the self [The Autistic Me 2001]. When viewed in this way control can therefore be seen as a form of multi-dimensional social process that helps people gain command over their own lives (Page and Czuba 1999). However, as a general definition I would suggest that empowerment through control is a process that fosters the capacity to put into action and realize the issues, events and experiences that each individual defines as significant to them. Control therefore can be seen as a process that is directly linked to the level of 'power' that an individual can exert over the things that they do and the things that they want, and the extent to which they are empowered through their attempts to gain and sustain influence over their lives. Foucault (1991) conceptualised power as being everywhere, diffused and embodied in discourse, knowledge and in what he terms 'regimes of truth'; power for Foucault is what makes us what we are. Control then can be seen as a way of independently asserting power to influence or direct people's behaviour or the course of events, and as can been seen in these examples as a means of personally influencing or regulating; time, space,

events, interpersonal contact and experiences. Essentially - influencing lived experiences in the world, influencing the life-world.

In this chapter I explore the suggestion, that through taking some form of control over duration, spaces, people and events, the subjects are attempting; to have agency over what outcomes are possible in different situations, to define themselves in some way as individuals and ultimately through this to gain some sense of control over their lives.

The participants have reported on the ways in which they believe the subjects carry this out, with three separate sub-themes identifiable within the main theme of control; these are described here as:

- Control over spaces / significant places.
- Control over people / a social process / withdrawal.
- Control over time / duration.

Each of these sub themes will be examined separately, with an overall summary of what this theme may represent for the subjects and the participants concluding this chapter.

5:3 Key Points

Concluding the analysis of each of the sets of extracts that are examined in this section I have provided a brief summation of the key points that are under discussion, this will act as a way in which to both capture the principle features within the interpretations presented and to draw together the central lines of enquiry as they develop.

5:4 Control of spaces / significant places

A number of authors have reported on the needs of some people on the autism spectrum for separate space away from others, for self imposed isolation and some of the difficulties they can often have with social interaction (Volkmar et al 1987; Freeman et al 1991; Capps, Yirmiya and Sigman 1992). For some people on the autism spectrum, behavioural challenges can often occur which may create a context of generalised social isolation and withdrawal (Heasley 2013). They may wish to spend a lot of time on their own, withdraw from social contact initiated by others or may become anxious in the presence of people. It has also been stated that though seemingly automatic and effortless, a person's determination of the appropriate

distance from others is a complex and dynamic social judgment that is simultaneously dependent on a number of factors, that include person familiarity, emotional state, age, gender, and situational context (Kennedy and Adolphus 2012).

For four out of the five subjects in this study, the need to take and maintain control over certain spaces in the home and to a lesser extent at school was a recurring theme that was reported by both staff and parents during the interviews. In the homes of the subjects that this related to the spaces that tended to be used were their bedrooms, and in some cases the toilet. At school these spaces tended to be the classroom, the toilet / shower areas or the soft play rooms that were available to the students either in the classrooms or close to them. The participants reported that these spaces had taken on a 'new meaning' and that the meanings of these spaces for the subjects had changed from what they had previously represented before the onset of adolescence. The need to be separate from other people, from family, and to restrict entry into certain key spaces was viewed as a central theme throughout the interviews.

Below are four extracts taken from the transcripts of three of the participants, which provide some evidence to illustrate the importance that these particular spaces came to represent for the subjects involved. Here I examine some of the ways in which three of the subjects demarcated spaces as important to them; how they separated their own spaces off from other people; how they communicated this to those around them and how each of the participants described their interpretation of this behaviour.

In these first two extracts which both relate to the same young man [Mahmud], control over his bedroom and a complete restriction on anybody entering it had led to a situation of separation from other members of the family.

Extract 1: 'We know not to go near his room now, before it was ok to go into his room, he even shared that room with his cousin, but now – no. He guards that door and gets stressed if we go near it. We've just picked up on it as a family – the room is out of bounds, simple as that'. (Transcript 7: Parent D / Mahmud)

Extract 2: 'He's got to be in control of the doors, especially his bedroom door – we don't know what to do about it! But if we shut the door or move it before he has finished shutting it in the way that he needs it to be shut, that's a big problem'. [Transcript 7: Parent D / Mahmud]

In these first two extracts it is possible to identify two separate scenarios whereby the subject has changed the function and meaning of the space [the bedroom] within the home. In the first extract there is some evidence to show that there is a raised level of tension within the family because of the apparent change in what the room now appears to represent for him. This raised level of tension is evidenced in the second extract where the participant describes how sensitive the subject is around any contact with the entrance to his room [the door]. What appears to be an abrupt change in the way in which the subject uses this space, and how that may impact on his interaction with those he lives with is of interest, as it has been suggested that:

> 'For some people with autism this is a long term way of being
> in the world. For others it is a phase, sometimes associated with
> a generalized loss of wellbeing. It can represent a change
> from a time when the person was more engaged socially,
> more accepting of being around other people and of
> co-operating with them'. (Clements and Zarkowska 2000:95)

The family of the subject in these two extracts appear to be sympathetic and understanding of the subject's need for isolation and this has led to what the family identify as a respectful approach towards his need for restricted access into this new found private space.

Key points: At present shared contact between the subject and family members has been curtailed which could possibly lead to the subject becoming even more isolated. The implications of this for the young man may entail a deepening of the separation and alienation from him and his family, and for him, an entrenched and fixed position developing around what this total control over his space now represents [for him]. This level of control may therefore have unforeseen ramifications for the subject such as withdrawal from the day to day experiences that the subject and the family had previously taken part in together. This may include changes to meal times, social activity and access to the wider community. Therefore the situations described above are potentially far more complex than just being able to allow the subject in these extracts to assert such high levels of influence over the

spaces he is controlling. This total control over space, may also act as a mechanism to close down access to events and experiences with others within the family that the subject does enjoy but now can no longer access. Seen from this perspective the impact of the subject's control over this space may therefore be far more complex and the impact potentially wide ranging. The family have accepted that the subject's room now represents something significant for him but this has directly impacted on the subject's cousin who has had to move out of the room. This has also led to the further complication that admittance in any way to this space is now extremely difficult for all family members. A critical point that has emerged from this situation is that the level of management and supervision of both the space and the behaviours presented by the subject are clearly significant.

In contrast to this is the situation of the subject in the following extract, who appears to use his control over a space in a classroom in the school in quite a different way.

Extract 3: 'He just likes to find that corner [in the classroom] and sit there, he may welcome you in, he may not, but he will let you know, and if it's a 'yes', then he'll bend forward and offer his head for a stroke, or he'll take your hand and place it on his head to be stroked' [From notes taken: Staff A / Min]

In this extract the subject appears to be far less restrictive about the way in which he seems to want to use the space he controls. He has also developed a highly interactive approach with the staff who work with him, which he uses to choose with whom he feels comfortable in sharing the space with, and he has developed a personalised communication technique that will indicate who is allowed in and who is not. This appears to be quite a sophisticated form of spatial control with an additional communication element built into it, and the staff who work with the subject have picked up on the nuances of the role they are required to adopt around this space. So in this instance, the subjects' control of this space is being used [in some form] as a communication tool in itself. When viewed in this way it could be argued that adolescence may have led in some way to the asserting of more control which in turn has given rise to the development of this new means of negotiated interaction.

Key points: there is a communicative component built into the way in which control of this space is managed by the subject, which is new and which had not previously been available for the people working with him. Control for this subject appears to be something he is willing

to share, and which can be separated into two discreet events. First, is a negotiated sharing of control over the level of influence another person has over the space he has demarcated as important to him, which is evidenced through the required form of communication from the subject towards another person around entrance into this space. Second, is the space itself which he is sharing and allowing access to, but only on his terms and only with the people he selects. In these extracts it is possible to see that both subjects are communicating to those around them how they wish to use these spaces, but in markedly different ways.

The fourth extract provides evidence of how one space has been used by one of the subjects as a designated safe place that he can be alone in, but also as a space that can be negotiated and one that can be accessed by other family members, at certain times.

Extract 4: 'I mean sometimes when he has come in, in the afternoon, if he's come in when I'm not here – and I've gone up to let him know that I'm here, I will get the resistance where he is pushing back the door [to his bedroom] to keep it shut. But, we can go in there at other times for sure, but we all know that there are times when we definitely - can't. [Transcript 9: Parent C / Chris]

In this extract the subject appears just as restrictive about the space he is controlling. He will allow people into his room at certain times, but he also regularly restricts entry to his mother and to the other members of the family. Admittance to this restricted space is permitted, but with less evidence of the type of close one to one interaction present in extract three. Here the parent and the rest of the family appear to be aware of the importance that the bedroom now holds for the subject, and the mother believes he is using the bedroom secured in this way, with him silently pushing back on the door, as a means to communicate that this is a place he requires others not to access at certain times as he wants to use this space to masturbate in.

The subjects' mother has made a decision about what this space may now represent for him and she does not go into the room until he has left it, or she waits until he is at school. The room is not such a restricted space as it is for the subject in extracts one and two, but it is believed by the mother to be used as described above [for masturbation] by the subject when he is in the home and appears to require time alone.

Key points: Here the subject's mother believes he is using his bedroom for behaviour that may have some form of sexualised characteristics to it; masturbation to ejaculation, exploration of his penis, exploration of his body for arousal. The bedroom is not completely out of bounds and has some form of a dual use at certain unspecified times of the day. Family members are allowed in to share time with him in the space, but there will be occasions when the room is used solely by the subject and he will communicate this by restricting access in the way described above – sitting with his back to the door so as to restrict entrance.

For the young men in these four extracts it appears that their relationships with the spaces available to them are changing, as these spaces have now become sites of negotiated power as what they wanted to do within the spaces was also changing. This has led to a series of renegotiations of ownership and control over these critical spaces with other family members and school staff, as well as changes in the ways in which the subjects and those around them relate to and interact with each other.

5:5 Control as a social process

Arguably, there is a renegotiation of identity taking place with some of the significant people around the subjects, through the way in which the use of control around these familiar spaces is now being used. There is a shift in position for the subjects in the extracts above, from one of being unable to control a space to being permitted some form of full or partial control of a space; a move from a disempowered dependent [negative] stance to a more empowered independent [positive] stance. This shift in position is being negotiated in one way or another between subjects and participants, within their relations with each other and within the way in which they socialise together. Shakespeare (1996) positions the identification of disability as a social process, one which promotes and maintains a 'negative' identity of the disabled person. He has suggested that the experience of disability as a negative identity arises out of a process of socialisation, or in the context of social relations. On an individual level he argues that the ability of a disabled person to do what they want and to be able to 'action' their lives is directly related to a number of factors: how a person is trained into certain ways of behaving, the extent to which another person is the subject of power over them, how a person understands their own capacities, how a person relates to others and the extent to which the person accepts the situation to be true for themselves personally. Seen in this

context the control exerted by the subjects over these spaces can be viewed as representing an attempt from them towards gaining some form of influence over features of their lives that had up to this point not been in their control. Challenging the level of power that other people have over their spaces, choosing who can and cannot enter a space and when and how long they can stay in that space. From this position the subjects can be seen as attempting to develop a new capacity to create an environment that they have ownership over. In essence, shifting the power that may reside within the existing social relationships that govern their lives from those around them – inwards towards themselves.

The question arises as to what options are available for the families during this period of change and renegotiation. This could take the form of simply respecting the young person's decision to choose a designated 'safe' space where they can go to when they are uncertain or uncomfortable with the environment around them. Brower (2007) suggests that this concept of the 'safe haven' is a vital factor to consider when working with young people on the autism spectrum. One critical issue inextricably linked to the notion of 'control' that faces both parents, staff and subjects during adolescence is that of 'privacy' and 'personal care'. This can be seen in this extract:

> 'for many years we're teaching our children to go with
> everyone and hold everyone's hand for safety issues
> and that it's OK to have someone help you get dressed
> and go to the bathroom, to shower you'.
> (Parent of a child with ASD [sic], in Ballan 2012:681).

Constant supervision and surveillance can be par for the course for people with any type of disability, with parents and staff routinely walking in during self care activities without asking permission. It is therefore not surprising that children with autism have a distorted understanding of privacy (Hingsburger 1994) - and who controls it. Young people with autism are used to having no control over who sees their body, and may subsequently have become desensitised to being seen naked. They experience less privacy and spend less time unsupervised and they experience greater dependence on their parents, and for longer (Hartman 2014:19). It could be argued that the level of control that disabled people are able to take over their environment and to what extent others [those people around them who have power] will let them have ownership of the spaces they choose, is I would argue

inextricably linked to the way in which identity formation during adolescence occurs. If 'Identity is the way people view themselves, how they view themselves in relation to others, and how they are viewed by others' (Swain and French 2008:67), then having power over the spaces you wish to spend your time in would arguably appear to be a decisive factor.

When a person can take control over the space they are in, they can begin to define what happens within that space. They can begin to develop a safe location from which to begin the process of validating who they are and what they represent, very much in the same way that many typically developing teenagers will decorate their walls or isolate themselves in their bedrooms. From this safe location the relationship between themselves and the people outside of this safe space can be regulated, safely negotiated and managed and the way in which they may decide how they intend to relate to others determined.

5:6 Controlled Withdrawal

Sharing time and space with others, and being part of a social system usually requires the individual to play an active role in establishing and maintaining relationships. However for some people on the autism spectrum sensory experiences and behavioural challenges can occur which can lead to self-imposed isolation. This position of isolation may be initiated by the person themselves through their own self agency, or because some disabling environments can present significant challenges that may make a person act in a way that challenges others and then they keep away from them.

> 'Having extremely sensitive senses especially to noise and visual stimuli can make me withdraw to my bedroom and not come out until I'm certain I'm the only one left in the house. This is when noise and even being in the same room with people I'm usually comfortable with is excruciatingly difficult'. (Roy 2011:1)

It may be of worth to consider exactly what this withdrawal or seclusion could possibly represent for the subjects in this study. From the outset of any form of discussion it has been suggested that a basic desire for 'aloneness and sameness' is central to the original assumptions made about autism, with descriptions of a form of extreme autistic aloneness that where possible, disregards, ignores, shuts out anything that comes to the child

from the outside (Kanner 1943). Or, perhaps as a counter balance to this position, it may be the case that people positioned on the autism spectrum simply wish to exclude themselves when necessary in order to focus on their own special interests, a position that these two comments posted on the Wrong Planet Autism Community Forum in 2008 appear to point towards;

> "...I don't shut out the outside world. I just don't relate to it
> In the same way most people do. And my internal world is often
> more important to me than the external world is..."
> [Comment 1]

> "...when I have to be alone, it means REALLY alone,
> physically separate. It almost hurts me to be near others
> in a similar way to noise can bug me to fever pitch. It's
> really hard to describe. When it gets really bad my mind
> totally shuts down like a body doing its own life support
> in the cold withdrawing the circulation from the extremities,
> just caring for the internal organs. I can just about feed
> myself but can't interact with anything at all. I can't bear
> people at all - they seem impossible..."
> [Comment 2]

One writer working from within the autism community comments on his experience of this situation of self imposed isolation or withdrawal stating that; 'one thing I have never felt is aloneness, although at times retreating to my own world, to my sincerest gratitude I have been motivated to be an intellectual, social individual' (Rubin: 2016:108). This writer's words appear to indicate how necessary it is to assume competence and comprehension in autistic individuals no matter how 'low' [sic] their 'functioning' appears to be, and to argue against the falseness of the myth of autism and the person alone (Chew 2006).

Does withdrawing into a personally elected space and being the only person allowed into that space provide a sense of control and an element of choice, in that through doing this the young person can decide who is allowed in and who is not? Hatton and Simpson (2012: 40) argue that primarily 'the reality is that it is important at all times to understand the nature of the autism for the individual'. They suggest that 'there are, of course many links and similarities between all people with autistic spectrum conditions, but individuals have their own personalities and so there are also key differences'. Could it be the case that these

differences form part of a new identity that these subjects are attempting to develop? One writer has argued that "autism is not a given condition or a set of realities; it is not 'given' or 'real' on its own. Rather, autism is and will be, in part, what any of us make of it" (Biklen 2005:65). Parents and professionals, teachers and therapists, must therefore constantly reflect on their preconceived notions of what this developmental condition is and what it can potentially represent as we continue to interact, understand, and be with those individuals who have a label of – autism.

5:7 Control: People - Positioning

Available within the transcripts are descriptions and depictions reported by the participants, of some of the changes in representation that appear to have occurred for the subjects around people who exist in their lives. This includes close family members and staff who live or work with the subjects in their homes and at school, who now appear to 'qualitatively' represent something different for them. I now want to examine how the participants have interpreted the impact of these changes on the way in which people are experienced by the subjects. This sub-theme was identifiable around one of the subjects in particular, and was absent from the transcripts of the other four parent participants. The subject was discussed by staff participants at the group meetings in terms of the way in which he used control as a way in which to reposition people, or to use them as a means by which he could 're-start' when he became 'stuck'. Characteristics of this behaviour were identifiable within the fractions [Spatiality and Temporality] and within the theme [Relationships] all reported by both staff and parent participants.

Below are three examples taken from the transcripts; two of the extracts are taken from separate staff participant meetings and one extract is taken from an interview with the subject's mother. What is under examination in these extracts is an experience not reported by the other interviewees, one which centres on a previously unseen extremely rigid representation of people that this subject exhibits, both at home and at school. People that the subject is spending time with and the position that they adopt in the spaces that the subject is in, appear to have become something that the subject now needs to have total influence over, in order to manage and take control of the space he is in.

Extract 5: 'He may place you – I mean, he may move you into the spot he needs you to be in' [From notes taken Staff meeting 1: Staff A / Subject: Mahmud]

Extract 6: 'For Mahmud everyone's got to be in the right position sometimes, this has got worse as he's got older, sometimes it's too much' [Transcript 7: Parent D / Subject: Mahmud]

Extract 7: 'If things go wrong Mahmud needs everybody to return back to where they were before things went wrong, it can't be sorted till everyone's back as they were' [From notes taken Staff meeting 2: Staff C / Subject: Mahmud]

In these three extracts the people around the subject Mahmud now appear to represent units or objects that require repositioning, and any previous interpersonal connection that had existed between the subject and his mother, family and support staff seems to have been replaced by this new controlling feature - positioning.

Key points: This trait has become one of the fundamental ways in which Mahmud now interacts with other people, and at school this behaviour has led to certain staff members becoming quite uncomfortable when working with him. However, controlling the positioning of people in this way is fraught with difficulties which can lead to situations of anxiety for the subject; as the people sharing space with him are unsure of exactly how they are to stand and for how long and in what posture, with the re-positioning of people experienced by the subject as both absolutely essential and extremely stressful. The staff also felt that this behaviour would be difficult to transfer into situations outside of the home and school environments. This had led to a series of changes to the subject's daily school experience. First, the subject was not able to go out with staff as much as some of the other students in the group, which had been typical before this new behaviour and something he had enjoyed doing. Second, any slight movement from where staff had been positioned caused huge anxiety for the subject. And third, entrance into the spaces the subject was working in was complicated to manage as any new person in the room would then need to either stay and be positioned or leave automatically; both outcomes presented difficulties for the subject to cope with.

It was this feature of the unmanageability of the experience for the subject and the difficulties the subject had around clearly communicating exactly what this experience represented for

him that stood out as the key issue within this scenario. However this experience of positioning can also transposed when seen in a different context; considering that from a very early age being repositioned by others is probably a very common experience for autistic children and yet when this situation is reversed this can make the adults around them feel extremely uncomfortable.

5:8 Control over time / duration

What became apparent when analysing the transcripts was the amount of reported incidents where the subjects had started to opt out or refuse to comply, especially around times of transition. This tended to occur in situations where the subjects were required to leave a space they felt comfortable in at a given time [e.g. when boarding the school bus in the morning]. Or, when the subject was using a room [e.g. the toilet or the bedroom] either as a place to masturbate in or as a place to simply be in. Or, when an event such as a lesson at school had come to an end and the subject had to leave the classroom as the school bus was waiting. The situations described in the following extracts show some examples of how the subjects took control of the time and duration of the spaces and situations they were in.

The first two extracts relate to one young man who shared his bedroom with his brother, and whose mother had a deeply positive approach towards his determination to gain control over crucial times during the day. She saw it as a way in which her son had tried to gain some form of power and influence over his own life and to some extent, over her. What she described as a positive approach to this had led to an atmosphere of calm acceptance within the home and in her opinion had lowered anxiety and stress for her son.

Extract 8: 'At first I was like 'oh god' you know, he's decided he wants to opt out and he's not co-operating, but then I looked at it in a positive way and he's realised that he has got some control'. I mean he aint got a lot of control, so I just went along with it' [Transcript 2: Parent E / Subject: Arran]

Extract 9: 'they [both brothers are positioned on the autism spectrum and both share the room together] simply won't come out of their room, sometimes all day, till they are hungry, sometimes it slows the whole day down'. So we've just gone, OK' [Transcript 2: Parent E / Subject: Arran]

In these two extracts the participant is describing a situation where there is no option other than to wait until the subject is ready to leave the space. This opens up the question of what the pressure imposed on the subject by knowing that he is being waited for might be like for him. Perhaps he resists leaving his room because he is attempting to take control over his role in what is happening next, or he is unable to leave his room because he is reacting to the expectations of those waiting for him outside of the space that he is attempting to be in control of. Here the mother of this young man is positively reinforcing his attempts at self agency around controlling his space and the amount of time spent in it. This has led to a relaxed and stress-free atmosphere between the subject and his family. Arguably controlling spaces such as bedrooms is a typically occurring event for any adolescent, and this scenario helps to illustrate how this type of behaviour can easily be misinterpreted when it is pathologised and viewed as a feature of the subject's autism instead of the act of an adolescent young man attempting to establish who he is and what he wants.

Conversely, the staff in these next two following extracts had to some extent viewed the subject's refusal to leave the classroom as a difficulty that they had to tolerate and find some way to manage, rather than as an attempt from the subject at control that they could embrace and collaborate in. The feeling from the staff participants in these extracts was that this situation could potentially create significant problems when the subject was outside of the school in the community and would be difficult to manage.

Extract 10: 'sometimes he's in there [the toilet] forever and we just have to wait. Sometimes it can get on your nerves because we can't do anything till he's finished. [From notes taken Staff meeting 2: Staff E / Subject: Mahmud]

Extract 11: 'at the end of the day he just won't or can't go until he is ready to go, one way or the other he is in charge of that classroom and we have to wait' [From notes taken: Staff A / Subject: Mahmud]

Key Points: in these two sets of extracts control appears to centre around the way in which the duration of events can be determined by the subject through opting out or through their refusal to comply. This has been interpreted by one participant as a positive characteristic and one way through which the subject can take control and have power and influence over what is happening to them and their role within that, whereas it has also been viewed as a

difficulty and a challenge for others. Once more, this behaviour is seen as potentially presenting challenges when it is transferred into situations outside of the home and school environments**.** Certain key spaces may inadvertently end up representing such a powerfully compelling personal experience for the subject, where their requirement to spend a considerable amount of time in one area can present issues around time restrictions that exist outside of their understanding. But it may also show the relative paucity of opportunities that young men with autism have around taking control of this aspect of their lives and how when they do, it has the potential to be seen as in some way problematic.

5:9 Summary

As reported in these extracts, non-co-operation and opting out of routines, changing the use of a space or a room and adopting a different way in which to engage with the people around them, appear to be some of the ways in which the subjects have attempted to indicate new characteristics of themselves to others. I would argue that these changes can be viewed as attempts by the subjects to regain or renegotiate some form of control over their lives and the level of influence they have over what happens to them. Goffman (1979:33) argues that 'we all seem to be inclined to identify people with characteristics which are of importance to us, or which we think must be of general importance'. What is of interest following this analysis is the importance that is placed on what could be argued are relatively minor events; preferring to stay in one place; choosing one person over another; requiring situations and events to be one way or another; developing new ways to communicate with those around us. These can be viewed as typical different ways in which identity is formed and developed, while also providing evidence of the levels of scrutiny that being disabled can bring with it. It has been suggested that disabled children have been marginalized by or excluded from the expectations, opportunities and aspirations afforded to so-called 'typically developing children' (Goodley et al 2015:7). I would argue that control as a lifelong continual experience, one that is exerted over disabled people, and control as a means by which disabled people have attempted to influence the world outside of them, are inextricably bound up within this process of identification, marginalisation and disempowerment.

In terms of the processes which I argue go towards the development of new forms of 'identity' for the subjects within this group, with attempts at control positioned very much within that

process, there is no evidence to assume that there is any form of global impairment in their social functioning (Happe 1994:35). People within the worlds of the subjects are still available as positive allies, and rich connections are clearly described in these extracts. In fact it has been argued that children positioned on the autism spectrum seem to show the same types of attachment behaviours which are no different from those of other (none autistic) children with Severe Learning Difficulties (Shapiro 1987, Mundy and Sigmuan1989). They appear to know about their own physical identity (Dawson & McKissick 1984), and they can recognise the faces of others (Ozonoff et al. 1990, and Asarnow et al 1991). They are able to respond differentially to different people and to different types of approach towards them (Clarke and Rutter 1981). Many autistic children are not aloof and do show proximity seeking behaviours and vocalisations for social attention (Sigmand et al. 1986, Sigmand and Mundy 1989). The subjects in these extracts, I would argue, are making attempts at contact [on their terms] and are drawing attention to what they require and what they need, which appears to be some form of control. But as is mentioned above, these young men are often communicating this in quite atypical ways that need decoding and as can be seen in some of the extracts this is not always sensitively recognised or negotiated.

The central themes that have emerged from the key points taken from this selection of extracts therefore appear to centre around the critical role that different forms of 'control' have played within the growing identity of each of the subjects in this study. The participants provide examples of the ways in which they believe control is taken and used in all of its different forms, and there is evidence within these extracts to show that this can on occasion be viewed in a positive way. The staff and parents have to some extent gained an understanding of the critical role that 'self determination' [defined here as; being in control over one's own course of action] can play during adolescence, and have on the whole adjusted to the different forms of control the subjects are presenting to those around them.

It has been suggested that `a person's identity is not to be found in behaviour nor - important though this is - in the reaction of others, but in the capacity to keep a particular narrative going' (Giddens 1991:54). This quote seems extremely pertinent when considering some of the different ways in which the subjects within this study have appeared to attempt to develop and individualise their own personal narratives through exerting control over the people, spaces and events that make up so much of their lives. Supported self determination

and assistance with the development of personal outcomes in whatever form they may take plays a central role in this process. Some of the component skills of self-determination may pose particular challenges to some young people on the autism spectrum due to potential difficulties in communication and social relationships that can be experienced by people in this population. But crucially, family and staff involvement, I would argue, can act as a critical variable, which can positively or negatively affect the development and expression of self-determination; this is clearly identifiable in some of the extracts.

How the subjects have used control is clearly understood by staff and parents in different ways. Some of the participants believed that this led to more positive outcomes for the subjects such as; increased power over spaces they have demarcated as private, more influence over the duration they spend on an activity, more influence over the people they choose to interact with, exclude or include into their lived experience and a lowering of stress. Others felt that it lead to more restrictive and disempowering experiences which resulted in a deterioration of behaviour, anxiety and stress for the subject and for those around them, confusion over different forms of response towards attempts at control that actually inhibit previous work, missed opportunities around collaboration and a subject/student centred model of working. What I am suggesting is that the comments contained in the transcripts above offer some evidence about how these young men are attempting to 're-create' and 're-take' control over their own sense of the contexts within which they find that they exist and how they may be are experiencing that.

In the following chapter I shift the focus away from this theme of control, towards another core theme that had emerged from my analysis of the data, which is that of relationships and the different forms in which they have been represented in this study. I examine this theme as it relates to key features found within this chapter and continue with an investigation of some of the subject matter and key issues already raised here. Features of control are inextricably connected with some of the ways in which the subjects have been reported to have developed or rejected contact with people in their lives and this will form one of the central areas of focus for the following chapter.

Chapter 6 Relationships

6:1 Introduction

In the previous chapter I presented an analysis of the way in which control was understood to have been used by the subjects, across three separate areas; control of spaces, control over time and duration and control over people. Through my analysis of the transcripts what also became evident were the frequency, regularity and impact of different forms of person centred connections on the subjects, significantly connections with chosen key people within their lives. This was apparent across all of the themes and sub-themes located within the data. As a result there emerged a second theme of 'relationships', one that was evident within all of the fractions - and that is presented here. I have presented this theme of relationships as a separate chapter in itself, as the evidence of some form of 'association/connection' aspect that I have located within the data, is clearly visible in the transcripts and appears fundamental to the way in which control had been used, adapted and developed by the subjects. In that any assertion of control by one person over another was likely to impact in some way upon their relationship.

Available within the transcripts taken from the eighteen interviews, are descriptions reported by the participants, of changes in the form of representation that appears to have occurred for the subjects during this phase of adolescence around certain people who exist in their lives. This has taken the form of changes in the way in which close family members, members of staff and certain students at the school attended by the subjects have altered and how they now appear to represent something qualitatively different.

In this chapter, the potential impact that this representational shift in the way in which people are experienced by the subjects, as it has been reported by the participants, is examined. I explore whether these apparent changes in relationships are all one way with the subjects changing how they are towards the participants; whether the participants have also changed the way in which they relate to the subjects or, whether evidence of change from both positions is available.

Hellemans et al (2010) carried out a research study with the carers of twenty four young men, some of whom had a diagnosis of autism and some who had other forms of learning disability. This particular study used interviews to explore what different forms of interpersonal contact

were taking place within this group. The study was able to describe a range of different person orientated behaviours that had been seen as occurring within this group during adolescence, which were centred on the ways in which the young men were acting or conducting themselves towards those around them. These behaviours ranged from kissing, cuddling and caressing other people that these young men had in some way chosen as representing something 'significant' for them, including instances of sexual intercourse. Within the same study three of the young men had talked specifically with their carer about the importance that they placed around the need for a close affective and/or sexual relationship or one that signified something essential to them. Their findings showed that the majority of adolescents and young adults with autism [sic] expressed sexual interest and displayed a variety of sexual behaviours. Within this study person-oriented sexual behaviour occurred frequently in both groups but the sexual developmental level reached by individuals with autism tended to be limited. The research subjects with autism were not significantly less sexually active than the individuals with other learning disabilities, almost half of the group talked about the need for a close affective and/or sexual relationship and six (30 %) of the research subjects with autism expressed their frustration about having difficulties in establishing a relationship.

In another study, Young, Gore and McCarthy (2012) examined the attitudes of staff supporting a group of people with learning difficulties within a residential setting, which focused on their personal understanding around sexuality in relation to gender. They found that within their study seven separate interviews contained evidence that suggested that some members of staff perceived men and women with learning difficulties as having different motivations for intimate relationships. No clarification about what form these 'different motivations' might be was available within the findings of this study, but the notion that there were different impulses around ways in which relationships were formed and what these relationships may represent was highlighted.

These two research papers appear to indicate two important things; first, that something active and observable is occurring in the lives of young adults with learning difficulties and with autism; something that may be linked to their developing sexual identity and potentially something linked with possible changes that they are undergoing during this adolescent phase. Second, that relationships and intimacy may very well be potential outcomes during this adolescent phase for young people with disabilities including those with autism. The key

point here is that negotiated forms of contact with 'others' has been observed by staff as being sought out for the purposes of familiarity, closeness and intimacy within these groups and that this is occurring during adolescence.

It has already been reported that individuals on the autism spectrum may share some of the familiar forms of desire for intimacy and companionship that people within the rest of the population may have (Wedmore 2011), and these two papers appear to provide some evidence that people positioned on the autism spectrum may indeed seek out and wish to develop intimate contact with others. This research may also indicate that there may be a motivation for people with learning difficulties, such as autism, to form relationships and to play an active role in their development and cessation with chosen people in different forms, on many levels and for a variety of different reasons.

Before moving on, I want to first clarify the way in which I intend to use the words representation and relationship within this study, as these are key phrases that are used throughout both this and other chapters they therefore require clarification.

6:2 Representation

Representation has been defined as a system of symbols which are used to make behaviour-generating decisions that anticipate events and relations in the environment (Gallistel 2001). Here, representation is characterised as a collection of things, perhaps judgements, or arrived at conclusions that are seen as working together as bits within an interconnecting network, a complex whole. In a linguistic study of the concept of representation Pitkin (1967) suggested that representation refers to a social relationship rather than to an attribute of the individual person, and that this social relationship could be meaningfully conceptualized only as a systemic property. For this study these features perfectly combine to provide a working definition of representation as I intend to use it, that is behaviour generated decisions/judgements presented through different forms of social interaction as a means through which to present the way in which a person, space or experience is negotiated, acted upon, embodied and given validation.

6.3 Relationships

There is a rich resource of information available online about what relationships can potentially represent for people with autism; on sites such as: [NAS 2016; The Mighty 2016; Ambitious about Autism 2016]. Available within these online resources are testimonies of people writing from within the autism community in which there are rich descriptions of some of the ways in which young autistic people have negotiated and coped with; contact with other people, developing relationships and maintaining friendships. However, to date very little work has been done on the ways in which those who do not access typical forms of communication and who present with the types of profiles of the subjects within this study cope with this. With this position very much a central feature of this study: Understanding what the difference may be between a relationship and a friendship, what intimacy may represent, what interpersonal contact may look like and what it is to choose someone as special or significant in some way - requires investigation.

Researchers who have undertaken the task of providing a conceptual investigation of the term relationship (Hinde 1979; Kelley et al 1983) have agreed that the very essence of an interpersonal relationship lies in the interactions that take place between the relationship partners (Reis et al 2000). Berscheid & Reis (1998) state that the defining hallmark of interaction is influence, with each partner's behaviour influencing the other partner's subsequent behaviour. As it is used in the context of this study the term 'relationship' will use this definition: Interactions and exchanges that take place between the two relationship partners. Koller (2000) suggests that, all children change and mature as they grow, that this is an important process that occurs in every individual and it is not limited by level of intellectual ability. The findings presented in this study provide evidence of examples of this type of development, change and transformation, and go some way towards illustrating the range of different forms of relationships that are available and that can be experienced by the subjects within this study, as reported by the staff that support them at school and by their families at home.

In the following extracts some examples of the different ways in which the subjects are believed by the participants to have experienced association with others are explored. From

the information collected across all eight of the fractions, relationships were shown to be directly related with two central sub- themes, which are:

- The experience the subjects have of relationships at home
- The experience the subjects have of relationships at school

6:4 Relationships at home

Using the interview data taken directly from the transcripts, I want to now examine the meanings that the parent participants attributed to the ways in which they felt certain relationships had either emerged or had changed since the onset of adolescence for the subjects. Looking at the impact that this had primarily on the subjects but also on those who were directly involved in each of the subject's lives.

These first two extracts describe two separate connections with other people that the participant's sons had both been involved in, these were described by both parents as previously having been very positive relationships, which had then appeared to have changed. For the participants the positive features of these relationships had been illustrated by closeness with other family members and through the subjects experiencing intimacy with others. This had been demonstrated by the subjects calm control with these individuals when sharing spaces, being attentive towards them and clearly indicating that they wanted to be around them. These were relationships that both the subjects and the individuals involved had played roles in, but which had over time become challenging for the subjects to engage with, and which had led to the closing down of contact between them.

Extract 1: 'Gerry's relationship with his carer completely broke down, they'd been what I would say was very close, really close and safe, but then there was a huge change, emotionally, to the point where he was extremely confrontational towards this carer, and that pretty much ended that relationship, she had to go - and she'd been with us and Gerry for a long time'. [Transcript 4: Parent A / subject: Gerry]

Extract 2: 'Mahmud was always close with his cousins, always with them, they took him out with them when they went anywhere, it was lovely, he used to share a room with his cousin, then that all stopped, now he doesn't like anyone coming in, anyone tries to enter, he gets

tense, he doesn't go out with them anymore, and his cousin now sleeps in another room'
[Transcript 7: Parent D / subject: Mahmud]

The termination of these relationships by the subjects is viewed as problematic by both families and linked in both cases with negative outcomes, and situations that both families would have to in some way recover from. In extract one Gerry has rejected contact with somebody previously close to him to the point where he now becomes distressed in her company. In extract two Mahmud has abandoned contact with all family members, a situation which has led to him having to guard his own private space and rejecting any attempts around supporting him in going out into the community. One clear issue across both of these extracts is the direct impact that this rejection of these key people, by both of the subjects, has had on the subjects themselves. This raises questions around: What type of change in the relationship has occurred? Why it has occurred at this point and not earlier? And, how are the subjects experiencing this change?

In extract one the previously secure relationship was with a carer who had up to that time played a significant role in the subject's life, but which following this change now meant that the family would need to re-employ another carer, and begin the process of building contact and trust between their son and a new person from the start again. In extract two, the breakdown in the relationship between the subject and his cousins had led to a change in sleeping arrangements within the home. For Gerry [the subject in Extract 1] the change in the relationship with his carer has led to a series of inter-connected outcomes for him: First he has either inadvertently lost or intentionally rejected contact with somebody he is reported to having previously appeared to feel secure and comfortable with, and he may be unsure of what the closing down of this contact now represents for him even if it is a situation that he has initiated himself. Second, his confrontational reaction towards the carer may have been misinterpreted and may have other meanings that now cannot be explored, as this person has left his life and any repairing or renegotiation of this relationship is now not a possible outcome. Third, if his behaviour has been misinterpreted, Gerry may experience a sense of disappointment or loss due to the breakdown of this relationship and the emotional impact of this may manifest itself in other potentially negative ways for him.

For Mahmud [the subject in Extract 2], this may also be the case. He may still be close to his cousins but because of the impact of changes that he seems to be undergoing as an adolescent he now rejects contact with them in the form in which it had existed previously. These relationships may now need to occur at a distance that he has control over, for a period of time that he is also in control of. This is not to say that contact between the subject and those around him have ended, it may simply have taken a different form and both the subject and the family are adjusting to this change.

Both subjects are experiencing 'direct' outcomes from what have been described as clear changes that they have expressed around relationships they have been involved in. This is not to down play the effect that these changes may bring to the way in which these families function, which could be considerable, but to challenge the interpretation of the participants and view the subjects re-representation of these people as potential communication attempts, or as requests to be heard, which I would argue would need to be a potential consideration.

In terms of how these situations above may relate to attempts by the young men towards their own individual identity formation, it has been argued that for young people emerging adulthood can mark the transition from the tentative explorations of adolescence to more serious and focussed attempts at self-definition (Jackson and Goossens 2006). It may be the case that for these subjects one feature of their own form of self-identification may potentially mean rejecting carers and family members. Perhaps because the individual qualities that they found compatible in these key people in pre-adolescence, have in some way shifted and they are now unable to accommodate what they had previously signified for them. How typical is it for young people who fall within this adolescent phase to close people out, and abruptly end contact with people around them and give no explanation as to why they have chosen to do this - I would argue that it is quite typical. The prominence of these important core people therefore may in fact play a key role during this transformative phase. Hirst (2004:13) suggests that 'the saliency of 'trusted' adults and reminders of selves as 'once young', in influencing young people's perspectives, actions and sense of agency should not be underestimated'. From this position these core adults who act as constants within the subjects lives, are therefore tasked to consider how changes in what people may represent

and how that is negotiated with the subjects, may in fact offer them a new role as guides during this period of change and allow their responses to take on a new sense of validity.

This presents questions around the ways in which people who are barred from typical forms of language are able to communicate and express their need for change in terms of the people who are close to them [family members] or [carers], when they are not able to articulate what they want to say themselves.

In contrast, the following extract describes a situation of acceptance rather than rejection and presents the subject as appearing to show a new type of interest in his brother, one that his mother has interpreted as in some way 'sexual', and one which has resulted in her withdrawing free access to the brother's bed room, a space that the subject has started to spend more time in than he did previously.

Extract 3 "I put a lock on B's [Chris's brother] door, cos Chris was going in there and standing there staring at B's feet, we didn't really know why. But I felt that he was displaying what I saw as a sexualised behaviour - in that way maybe I'm wrong - who knows, but I've got to teach him somehow' [Transcript 9: Parent C / subject: Chris].

In this example Chris's mother is confronted with the situation of having to restrict access to his brother's room because she believes that Chris has begun to represent his brother in some type of negative 'inappropriate' sexualised way. Haracopos (1995) addresses this type of situation by stating that when an autistic person directs his or her sexual interest to another person, one should decide how far to go in supporting such a contact, since to experience sexuality with another person can consist of showing tenderness, care and empathy, one must recognize that some people with autism have extreme difficulty in relating to other people. Shapiro and Rich (1999) take this a stage further, stating that autistic people may do and say many things that violate most people's social context without realising that there is something they are violating. The social isolation that can result from this may increase their loneliness and their feelings of being different. Violation of social norms may therefore occur with ease and without any real consideration of what the impact may be.

However, as Koller (2000:15) states 'being autistic does not mean being unable to learn'. Teaching methods, and in this extract I would argue that the subject's mother is very much

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attempting to provide her son with some form of understanding around what you can and can't do in a private space, may simply need to be adapted, to accommodate this individual's learning style, special interest, and immediate need. Another interpretation may be that the mother is simply trying to protect her other son from sexual interference, or that she is reacting against the suggestion of some form of sexual attraction from one brother to the other. Whatever the premise from which the subject's behaviour is viewed, teaching and learning around what is appropriate and not appropriate is what the mother feels she is tasked with, and that may occur with her positioned in the role of teacher, enabler, protector or mother. Writing about personal relationships and sexuality for people with learning difficulties, Craft (1994) has suggested that as teachers, and arguably the mother in extract three is tasked to take on this responsibility of teacher for her son, we are required to take on a number of separate but at the same time interconnected roles. First as a teacher there is a need to feel competent and comfortable around the skills you are trying to teach and you need to have an understanding of the individual needs of the person. Second as a protector you have a responsibility towards the personal integrity and safety of the individual because as a group, young people with learning difficulties are likely to have increased vulnerability. Third, as an intervener where a particular sexual behaviour brings a person with a learning difficulty into conflict with societal boundaries, it may be necessary to intervene and re-direct them away from a potentially complex situation. Fourth, as an empowerer you are enabling the individual by a process of encouragement, facilitation and the imparting of skills to exercise power over their own lives and to make their own choices at their own pace.

Nevertheless, the impairment in 'social awareness' and 'reciprocal interaction' for the learning and understanding of appropriate sexual interaction can be profound in autism (Ruble 1992). This may not necessarily always be the case but needs to be borne in mind as a feature of this particular form of developmental condition. Taking the perspectives of other individuals (Baron-Cohen et al 1985) and considering their own and others viewpoints (Baron-Cohen et al 1985; Howlin, 1986) may confound sexual development and can contribute to forms of behaviour that may challenge the tolerance, understanding and knowledge of families and support staff working with young adults on the autism spectrum who are going through adolescence and encountering instances of change and transformation.

It may be the case that what can be described as socially unacceptable sexual behaviour such as in this situation - the compulsive objectification over the subject's brother's feet and viewing his brother simply as an object that he is observing as a form of arousal - may indeed in some way be related to some core features of autism. Why can't the subject just enjoy his brother's body? Is it because he is living outside of the taboos generated, shared and policed within society? What feature of this behaviour was inappropriate? Does its inappropriateness lay in the lack of reciprocation between the subject and his brother? Or, is it an issue of consent. Is the negative connotation attached by the mother warranted, or as has been explored in the previous chapter, is it a question of socialization, considering that normally [sic] developing children learn to be discrete and selective in the display of behaviours at a very young age (Gil 1993).

For the young man in this extract, it may or may not be the case that the necessary skills required in order for him to develop a more socially acceptable form of contact with his brother reside within the family. And, the translation of these skills into an understandable script that the subject could access efficiently may require a significant level of patience and time. Hingsburger, Griffiths, and Quinsey (1991) offer an insight into this situation, suggesting that inappropriate sexual expression may result from default as the only allowable expression of sexuality, in an environmental context that does not support appropriate sexual knowledge and relationships for individuals with autism.

An alternative outcome in terms of the way in which a familiar person within the family can be re-represented can be seen In the following example, where another of the subjects has also started to interact with a member of his family in a completely different way, one which his mother views as wholly positive and which is embraced by the entire family and viewed as completely appropriate. This positive representation of appropriate intimacy between a young man on the autism spectrum and his sister very much bears out this statement by Shapiro and Rich (1999) when they state that people with autism do interact and form relationships, but of a different nature. And, that many of them have a strong desire to be with other people, to express themselves and to be understood.

Extract 4 "Arran has developed a new type of relationship with his sister, its lovely to watch, they are close but it's wholly their thing, they watch certain things on the TV together, they

have their own little spot on the couch, they even have their own private form of Makaton, no one is allowed into this and this has happened really over the past couple of years..." [Transcript 2: Parent E / subject: Arran]

In this example the now adolescent subject's attempts at cultivating a new form of intimate relationship with somebody he already had a secure relationship with as a child, have been positively encouraged and endorsed within the culture of the family as entirely appropriate. In this scenario the subject's family are positioned very much as his allies around his attempts at intimacy which involve; shared language, choosing to be together but apart from others, special interests that are unique to this couple, the subject being able to explore what it is to be intimate with another. From this supported position the result has been a lowering of stress and a development in communication – both positive outcomes for the subject and his sister. Liddiard's work on forms of intimate citizenship some of which she argues may be outside of any type of sexual intimacy is of interest here, as it presents some of the barriers around what she describes as labelled people's lack of control or access to relationships. Ignagni, Liddiard et al (2016:133) have commented on how 'Labelled people described the ways in which they are not allowed to love – prevented from having friendships, from having relationships'. It may be the case that the young man in this extract is in some way experiencing or exploring some or all of the features of a form of 'sexuality', Lawson (2004:32) states that sexuality can be composed of a number of 'facets' and that it can be viewed as a type of rite of passage. According to Havighurst, as cited in Schopler and Mesibov (1993) an individual needs to experience a range of developmental tasks in order to develop and grow as an person, some of which the subject in the extract above arguably does, as there is clear evidence that:

- New and more mature relations with a peer have developed.
- Clearly defined social roles are available within this contact.
- The subject has been able to build and develop the relationship with his sister over time.
- He has achieved emotional independence from his parents.
- He has selected the person he wishes to attend to.
- For the subject it has been reported that there is an element of anticipation and excitement around time spent between him and his sister.

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- There is the potential for the development of intellectual skills.

- The subject appears to desire and achieve a socially responsible behaviour.

- Within this relationship a mutually accessible set of values around proximity, touch and appropriateness are present.

These characteristics can be seen as representing a loose collection of qualities or tasks that go some way towards describing a positive experience of relating with another, and how connectedness is acquired and nurtured. What marks it as distinct is in the way that it is represented in a positive form and one that this subject has arguably taken part in and has a high level of control over. Pukki (2003) as cited in Lawson (2005) suggests that in terms of sexual expression; there is very little in terms of the positive in respect to what autistic people actually enjoy, and how one might move towards and also recognise, good [positive for them] experience. Emotions are typically managed or regulated by those supporting people with autism from a 'deficit' point of view or not at all. For example, the terms 'obsession', 'infatuation' and 'fierce attachment' are often used to describe the behaviours of autistic individuals, never using the terminology generally applied with 'normal' young people, such as 'falling in love' or 'having a crush' on somebody.

Has the young man in the extract fallen in love with his sister? Does he have a crush on her? Is that possible? Is that appropriate? Is that something that the family would want to support and assist him in? This situation arguably throws up a series of important questions around the ways in which expressions of intimacy are validated for people with different developmental trajectories, this example could easily be viewed as a 'positive' and appropriate attempt at interpersonal contact that has been supported by the family.

Sicile-Kira (2008:20) argues that, 'The challenges of having a brother or sister on the autism spectrum can have both positive and negative effects on a sibling. The factors that affect how a sibling adjusts include family size, severity of the brother or sister's impairment, age of the sibling at the time of the diagnosis, gender and age of sibling, and their place in the birth order. The parents' attitudes and expectations have a strong bearing on how a sibling adjusts'. In this extract the subject's sister has agreed to play a positive role in the development of this connection and the parents approach is supportive of her role as a 'special chosen person' within the family, in order for their son to safely experience what it may be like to explore the

subtleties of expressing intimacy with another person. Schopler and Mesibov (1993) have argued that concerns about expressions of sexuality and the appearance of autism can be influenced by two things: The people who are there to support the individual's sexual rights' and the community's fear of the sexuality of the individual with autism. However, the questions arise: How can the parents prepare their son for an intimate relationship if the relationship they may be preparing him for is with another family member? Or indeed should they be developing this connection? Even if it is an appropriate connection that takes place largely in the home and one that the other sibling has given consent to and is supportive of. For this young man adolescence has led to a new level of closeness and a different form of intimacy with his sister that, carried out in the wholly appropriate way that it is, pleases both of him, his sister and his family.

Both of these extracts show two quite different situations, which involve siblings who now have to re-negotiate their roles and relationships and their responses to their brothers, as what they had previously represented has changed and they now constitute something different, and their previous roles may need adaptation.

Conversely, in the following extract the subject's mother is expressing her fears around the changes that she is beginning to experience with her son around his personal care; she feels that there has been a change in their relationship and the immediate impact of this change on her son is clear.

Extract 5" Min is more anxious, especially when I am washing him or bathing him or when I change him in the night, I can remember when I could just relax with him, but now I can't, he's more anxious around me, he is becoming a man and I am really struggling with it" [Transcript 6: Parent B / Min]

Here, the subject is described as exhibiting 'anxiety' around his mother, where before washing at bath time had been a relaxed experience. In this extract his mother now appears to represent something that creates a sense of unease in the subject and his mother is uncomfortable with the change that she is experiencing with him. Previously bath time and bed time had been times that they had shared together, where the mother had taken care of her son's personal care and her role as carer was clear and delineated. Now these times have become times which require re-negotiation between mother and son, as they involve close

personal contact and touch, removal of clothing, and spending time with the subject when he may be aroused or in a state of confusion about what his body now feels like and how that impacts on his mother. The mother's struggle I would contend is now expressed through tension and he may well be picking up on this and reacting to it.

Key Points: Intimacy with some family members may have changed for some of the subjects in these extracts into what could outwardly appear to be ambivalence towards them. Some of the subjects within this study have been reported as being completely unaware of those around them and oblivious to the impact of their behaviour on them, and in these instances there may be no immediate way in which to address the change in the relationships. In extract one, what appears to be a breakdown in contact between the subject and his carer can also be viewed as the subject choosing to change the way he interacts with this person, or simply him preferring not to share space with them or changing the way he spends time with them at that particular time. It is the parents who describe this as a 'breakdown', when in fact it may not be. This may mean that the subject becomes more isolated, or that key people are replaced when they need not be, when they simply may have needed to adopt a different role around the subject which may be what the subject required. This may mean that the person exits the life of the subject for good, although they the subject may not be aware of this and may not have wanted this.

In extract three, there is evidence to support the suggestion that some of the features of the new type of relationship that the subject appears to be developing with his brother have within them an element of objectification and arousal, which may be sexual in some way. His mother describes it as such and his attempts at connecting with his brother in the way that he has tried to do, has led to access to his brother's room being restricted. This would no doubt have a negative impact on the subject and one that would lead to stress and frustration for him. Yet this was necessitated by the duty of care that the mother felt was needed to keep her other son from being placed in a position of risk. Risk from his own brother potentially wanting to be intimate in a way that defies social convention and typical understanding.

However, a shift in the way in which one family member may be represented can be viewed as a very positive experience, leading to new forms of appropriate intimate contact. This is described in extract four. Here the subject is experiencing a sense of calm control as he plays

a meaningful role within the developing relationship he has initiated with another family member. Here the subject has the freedom to express himself; it is supported by the other person and by the family and the subject's attempts at wholly appropriate forms of interaction and intimacy are not in any way thwarted or stopped, as they fall, for this family, within the range of socially acceptable behaviour and appropriateness.

For one parent, supporting their son with his own personal care [e.g. bathing, toileting, showering] presents huge difficulties as he appears to now experience his relationship with his mother, who is his primary carer as full of anxiety. This makes it stressful for him and his mother. This shift from carer to enabler may be difficult for some parents to cope with, especially if they are single parents with younger children to care for, who may struggle to cope with the complexities of the changes that adolescence may bring, as is the case with Min's mother.

With the points raised above very much in mind, I want to now examine data taken from the interviews and group meetings with the school staff in order to examine some of the ways in which evidence of the impact of relationships are believed to have been observed and interpreted within this setting.

6:5 Relationships at School

Contact with other people within the setting of the school, has provided scope for new types of relationships to form. This has occurred naturally as the subjects regularly had more opportunity to develop contact with peers and staff over time, because they spent more time together throughout the school day and had more access to the spaces and shared events and activities that they took part in together.

The participants felt that purely functional types of relationships between staff and the subjects were already in place. This included the connections between bus escorts and midday supervisors, special needs professionals and other support staff working within the school who supported these young men. In addition to this the participants also believed that the subjects were fully aware of the other students they spent time with and had in their own individual ways learnt to relate to them, be it very passively [appearing ambivalent to them or calm in the company] or on occasion in more active ways [directly engaging with them in

lessons, at lunchtime or on the play decks]. However, what was of interest is the way in which the subjects, during adolescence, have appeared to adopt a different position towards some members of staff and some of their peers.

Below are a selection of extracts taken from the transcripts provided by the staff participants who work with the subjects at the school. These extracts were selected because of the clear descriptions captured within them of situations that showed the subjects developing new and markedly different forms of connections with other students and staff. Connections that the staff who support them had not previously witnessed before. Here the participants provide their interpretations of how the students have begun to represent certain people in the school in qualitatively different ways, which may indicate a requirement for some form of intimacy or closeness or a single focus connection on the attributes of that person and evidence of connections that have formed between the subjects and members of staff.

The first two extracts describe situations that the staff participants had been personally involved in, whereby two of the subjects have unexpectedly begun to focus solely on two other students in the school.

Extract 6 "It was like Mahmud hadn't even noticed B, I mean they'd been in the same class for like years and then suddenly, boom, he's all over her, so we had to do something about that! To start with he didn't like us separating them apart, he got stressed, and she got stressed cos suddenly everything is different." [Transcript 2: Staff D / Subject: Mahmud]

Extract 7 "Chris would just wait outside the classroom trying to catch a glimpse of M, anything to see him, he'd have stayed up there all day if we'd have let him, and it all seemed to happen when they went up to the top floor [Sixth form]. We had to put a bit of paper up over the window to the class, it was tricky." [Transcript 2: Staff A / Subject Chris]

These examples would appear to indicate that the subjects in these extracts have in some way selected these other students as representing something vital for them now or significant in a new way that before had not existed for them.

In extract six the staff participant had been placed in a position where she had to intervene between the subject and the student, primarily to maintain the safety of the chosen student who now represented something hugely compelling for the subject. This had initially led to a revision of the interaction approach and transition support strategies around the subject and the student when they were in close proximity to each other, in order that they could share a classroom space with each other. But the situation deteriorated and eventually the other student was removed from the class room and placed into another group. I would argue that the negative impact of this separation between the subject and the object of their affection was in this case not fully recognised.

Other issues that needed to be addressed were the fundamental changes in the ways in which the school day was organised and structured [lunchtime, playground time, sessions they had shared, toileting, swimming]. Also, there was a requirement of the class team that they develop sensitive and individually supportive measures in order to ensure that both students were supported during this phase. For each of the subjects initially this had meant a number of significant changes.

For the subject in extract six the person he had shown interest in was removed from his immediate world, in that he was not permitted access to the spaces that she was in and if he did share space with her it was closely managed and any attempts from him towards making contact with her were stopped. Secondly, social times when they would be in each other's shared space with other students was also now scrutinised and managed so that he could not make contact with her. Seen in this way, the subject's attempts at contact had been marked by removal of the person he had indicated an interest in, increased scrutiny over him and an almost complete change in his routine.

For the subject in extract seven visual access to the person he had shown interest in was denied with the window to the classroom covered in order to block the subject's attempts at looking into the class, and extra staff were allocated to both students especially around times such as playtime and assembly time when movement around the school was looser and when there was more opportunity for this subject to seek this student out. Therefore, the subject's attempts at contact had been marked by all forms of access to the student he had shown

interest in being denied, with higher staff to student ratio throughout the day and increased scrutiny over him.

The outcomes for both of the subjects therefore led to restriction from spaces, opportunities for contact stopped, more close management of the subjects, more control exerted over them and limited time spent in shared spaces.

The wider issues exposed here are that when the subject in extract six showed interest towards another student it was problematised and viewed as a risk by the staff. For the support staff; the fear of unknown outcomes; intimacy between the subject and the other student [which was viewed as something that staff were not able to control and as something that the staff had to provide protection against] had led to a change in the way in which these two students were supported in the classroom. This approach could potentially lead to the subject being withdrawn from the class altogether and separated from the other student completely.

Both situations were viewed as problems that required staff to find solutions to, even though they contravened the desires of the subject. It may be the case that the expected outcomes envisaged for the subjects in the extracts above are not compatible with those of the staff supporting them, in that there may be a friction between what the subjects' expectations and aspirations around what they desire are and what would typically be acceptable. This presents the question; what do disabled children do to the widely held phenomenon of the 'normally developing child?' (Goodley & Runswick Cole 2014:7). I would answer by stating that the subjects in the extracts above appear to have presented a challenge for those supporting them. They have asked of these staff to consider; what opportunities are there for me? How comfortable do you feel in facilitating those opportunities if they rub uncomfortably against your own values? These authors suggest that the lives of disabled children and young people demand us to think in ways that affirm the inherent humanness in their lives but also allow us to consider their disruptive potential. And this disruption of the forms in which desire and longing can be represented can for some be an uncomfortable proposition to consider.

A different form of connection between one of the subjects and two students in their class is captured in this next extract, where the staff participants describe how the subject has started

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to adjust his behaviour around the way in which he responds to these students. The staff participant especially draws attention to the fact that the subject will now make appropriate physical contact with one of the students that they had previously been defiantly oppositional towards. Here, I am suggesting that one of the things that has emerged from my analysis is evidence that for some young people with autism, adolescence can often mean the advent of a time of transformation in relationships with peers. This can take the form of a shift from ambivalence to desire around a peer known to them, or as a move from opposition and separation to togetherness and calm control.

Extract 8 " He's definitely more comfortable with A and T in that class now, he used to run around that room smacking everyone he came near but now he is calm, he'll even take A's hand when we go out, really softly, it's like he knows them now. He will always want to hold her hand when we go to the shops, hers and no one else's'. [Notes from staff meeting: Staff B / Subject Min].

Key points: In this extract the subject has shown ['by taking the students hand' instead of 'smacking the student'] that this person now represents something new and positive in some way to them, and that their [the subject's] form of contact now represents something new and different; potentially: I feel comfortable with you now, or I feel comfortable because of you, I can see that you are something / someone that has a special positive meaning to me now, one that previously you did not. This acceptance of a person previously known but now of significant importance is borne out below.

In the following extracts are two descriptions of relationships that have been observed between members of staff and two of the subjects that clearly have some element of intimacy within them and which appear of value to both staff member and subject. Both of the staff have worked with the subjects for some considerable time and know them well.

Extract 9 "I reckon that because we work with him on a day to day basis he is quite tuned into us. We are tuned into them and they are tuned into us. I think it's both. You know I've seen Arran when he works with H [his ABA worker] and they have a really tight connection a real bond and a real what I would call friendship" [Transcript 5: Staff F / Subject Arran]

Extract 10 'A works with Gerry in a way that nobody else can, she knows him inside out and he trusts her totally, when he's in a crisis you call for A, because he won't calm down for anyone else. They know each other well, he trusts her and let me tell you he don't trust a lot of people.' [Transcript 8: Staff F / Subject Gerry]

Whether changes that have taken place during adolescence have led to these new connections developing between the two subjects in these extracts and the two staff members who support them, is open to debate. What is clearly evident is that the subjects and these people know each other; they relate to each other, these members of staff have not been discarded by the subjects. In fact the subjects have developed profound contact with them, closeness and trust.

Key points: There are some interpretations described above that are shared by both staff and parents and which point towards some form of mutually accessible experience, such as; the impact that a change in what a family member, carer, or staff member might represent for the subject in terms of physical contact, intimacy, spending time together, the role they play when the subject was in distress. The comment from [Extract 5, Parent E, Transcript 1] describes a complex situation where she is unable to shift out of her role as the primary carer for her son, a situation which has brought her into a state of conflict with the considerable physical changes that her son is going through. In this case she was unable to access additional support and was required to continue with this role even though she felt it was no longer appropriate for her. Whereas the comment from [Extract 4, Parent D, Transcript 2] describes a completely new form of relationship between brother and sister that is accessible, relaxed and calming for the subject and one that they can appear to both benefit from.

What appears to be revealed from my analysis of the data is that relationships are both possible for these young men and quite typical. They can be experienced in various forms, they are occasionally initiated by the subject or they can be developed collaboratively with another person, the subjects have some level of commitment to them and in individual situations control over certain features of them.

The information in these transcripts points towards a series of different scenarios, where relationships will form, occasionally deteriorating, re-forming and re-adapting, sometimes

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leading to isolation for a period of time, occasionally leading to situations of intimacy. Speaking about the ways in which people on the autism spectrum may cope with the mechanics of how to develop and maintain a relationship between themselves and another person, Vermeulen (2006:48) states that 'adapting ourselves to social behaviour happens through our ability to 'sense' context'. I would argue that the comments contained in these extracts offers some evidence about how these young men are attempting to create and control their own sense of the context of the relationships they exist within. They are negotiating how they can choose to 'opt out', how they can choose to 'change the context' and 'shift the way in which they represent themselves' within the relationship, with the person they have chosen or with the person they are in the process of choosing. The context may not fixed, and it may be the case that neither are the positions and roles of the people involved and what they may represent.

6:6 Summary

Esmail and Darry et al (2010) in a paper that focussed on the current societal perceptions and attitudes towards sexuality and disability found that generally at a societal level there was a reluctance towards any attempt at initiating relationships with individuals with disabilities. Descriptions of the manifestation of autism in childhood tend to highlight the pervasive limitations of individuals with this disorder [sic] in the "basic building blocks for interpersonal relationships" (Travis & Sigman, 1998:65). Seen from these positions the suggestion seems to be that relationships for people with learning difficulties and especially for people positioned on the autism spectrum represent something that is 'negative and limited'. And yet within these extracts there is clear evidence that autistic people both seek out, develop and successfully engage in a range of different forms of relationships with a changing selection of people throughout adolescence, both within their peer group and with other significant people in their lives. Laing (1969) argues that interpersonal life is conducted in a nexus of persons, in which each person is guessing, assuming, inferring, believing, trusting, or suspecting about the other's experience, motives, and intentions. He goes further, suggesting that only when two people carry out reciprocally 'successful' acts of attribution can any genuine relationship between them begin. It has been argued that this view of language, mind, meaning and selfhood is constructed through 'dialogue', with the emphasis being that we are not "self-contained" selves (Sampson, 1989), but that we 'owe our character as the

individuals that we are to our living, embodied relations to the others and otherness's around us' (Shotter and Bayer 1998:1).

What I have presented in this chapter are a collection of descriptions of situations which illustrate how the subjects have either developed and nurtured a connection with another person, where they have been supported by parents or by a member of staff or where they have brought existing relationships to a close, usually within a wider interconnected pool of people that are available to them. What appears to be clear from the information available within this selection of extracts taken from the transcripts is that relationships are both possible and quite typical for these young men, that they can exist in many forms, are changeable and that they are achievable. The information in these transcripts points towards a series of different scenarios, where relationships will form, occasionally deteriorating, re-forming and re-adapting, sometimes leading to isolation for a period of time, occasionally leading to situations of intimacy. It has been suggested that on a visual level, there are certain actions or gestures that we know and interpret as intimate: kissing, touching someone else's face, their hands or other body parts. Not only do all of these tend to present a challenge for individuals on the autism spectrum who have certain sensory issues, but visual depictions stop at the surface, and are merely the tip of the intimacy iceberg. For people on the autism spectrum, intimacy can and often does look different. Nevertheless just because others fail to recognise it does not mean it is not there. Sometimes intimacy is simply sitting quietly in the same room with someone, tolerating their presence in your private environment. Whatever form it may take, intimacy runs deep, and there is no one way—no right or wrong way—to be intimate with someone (Gravino 2016)

For the subjects, from the available responses that are available within this nexus of characters, person orientated connections have both formed and eroded. Particular connections with primary carers [parents] have become dysfunctional and obsolete and established connections with known support staff have deteriorated, leading to these people having less and in some cases no direct contact with the subjects. Tentative explorations of physical contact with previously ignored classmates have become possible, and powerful connections have been made towards other peers. Family members have been chosen as representing something different and intimate, other family members have been discarded, while new forms of relationships are being negotiated and mediated. Evidence of the

attempts towards some form of connectivity between the subjects and people chosen as special to them are available within the transcripts. Reframing these behaviours that the participants have described in these extracts as potential communicative acts, and as attempts from the subjects at actioning change around the people that they represent as 'significant' or 'not significant' to them personally, will form the basis for the continuation of my analysis of the data.

In the previous two chapters I have presented an exploration of two of the central themes that have emerged from the data, the first of these themes was control. In that chapter I examined how the participants had interpreted some of the ways in which they believed control was used by the subjects across three separate identified areas: control over certain key spaces, control over time/duration and control over some of the people in their lives. I put forward the suggestion that through taking some form of control over spaces, people and events, the subjects were presenting clear evidence of their attempts towards gaining agency over what outcomes were possible for them in different situations, how they utilised control as a way in which to define themselves as individuals and how they were able to gain some sense of power over their lives. The second identifiable theme was relationships. In this chapter I explored descriptions provided by the participants of what they felt were representational changes in some of the types of relationships that the subjects had with certain people in their lives: mother and father, sister and brother, support staff and other students. In this chapter I explored changes that the participants felt had occurred for the subjects during adolescence. I provided an examination of what meanings the parents and staff felt these changes had for the subjects and I looked at how that was negotiated between the subjects and the participants, exploring the potential meanings of these new evolving types of connections.

In the next chapter I explore the third theme to emerge from the data, that of Communication. I examine the different ways in which the subjects have communicated with those around them during adolescence, how they have alerted the staff at school and family members at home to what their needs are and I look at the different ways that staff and parents alike have interpreted and acted on these attempts at communication. The forms of interaction used by the subjects are highly individualised and not dependent on spoken forms of language, therefore remaining open to the individual interpretation and personal

understanding of the people around them, and some of the tensions that can exist around this position will be explored.

Chapter 7 Communication

7:1 Introduction

What became evident through my examination of the two themes already discussed in this section were the different forms in which the participants had felt the subjects had transmitted information about their interior worlds to those around them, the pivotal role these highly individualised forms of communication had played, and the ways in which these had been interpreted and acted upon. Through an analysis of the data, the acts of communication between subject and participant and their impact on both parties has emerged as a significant theme in its own right and a critical feature consistent throughout the transcripts, important enough for it to be represented as a theme in itself and one that requires individual examination. In this chapter I examine the outward representation and the impact of some of the different forms of communication that the subjects in this study have presented, in order to gain a deeper understanding of the means by which the subjects are attempting to articulate what they want to communicate to those around them. I will explore some of the ways in which these exchanges have been perceived and interpreted by the parent and staff participants, and examine how these different forms of articulacy are being recognized and responded to. Through exploring these alternative forms of articulacy it may be the case that what has become available within the data could indicate towards an entirely different way of relating language to the body, words to the world, culture to nature – in essence a different form of subject being (Weiss et al 2008).

7:2 Communication

As it is used in the context of this study 'Communication' is defined as; something that occurs when one person sends a message to another person either verbally or non-verbally (NAS 2016). If this act of communication occurs in some form, then the suggestion is that this may potentially lead to further ongoing interaction, which is what would typically take place when two people then respond to each other – a two way transmission. Autism, is a developmental condition that may affect the ways in which a person communicates [transmits] with and relates to other people. Individuals with autism may have trouble interacting with others and may often withdraw from their environment, and while the severity or mildness of the condition is unique to each individual, communication barriers tend to be common (Special

learning Inc: website 2016). Autistic children have been found to possess a more limited repertoire of communicative functions than their peers, with particular difficulties in utilizing communication for social or interactive purposes (Stone and Caro-Martinez 1990). One of the defining features common to all of the subjects within this study is that they are not able to always efficiently take part in this type of two way transmission, or that they take part in it in highly individualised ways. In general the subjects have struggled to access typical forms of spoken communication or to use a range of alternative and augmentative communication systems such as: Makaton, a language programme which utilizes signs and symbols to help people to communicate; Picture Exchange Communication Systems (PECS); Voice Output Communication Aids (VOCA) aka Speech Generating Devices (SGD) and Objects of reference (OR) an approach that uses any object systematically to represent an item, activity, place, or person. The subjects within this study are not able to easily convey information about: what they may require; what they may be experiencing; how they are coping with any changes they may be going through; how they wish to represent themselves or who they are becoming. Compounding this, their individual forms of communication may not always be clear to decode or easy to understand; they may remain hidden or embedded in other behaviours, difficult to make out and hard to interpret by those around them. It may be the case that regardless of language ability people positioned on the autism spectrum may well have considerable problems using language in any form to communicate or in understanding how others do so (Jordan & Jones 1999). Subsequent problems with comprehension, reading for meaning, issues with empathy and social priorities can all influence how autistic people see the world. Lawson (2004:24) addresses this communication dilemma, when she writes that 'when one draws from a different pool, sings a different song, beats a different drum and encounters the realities of life from a different perspective – communication can be difficult'. From this position it can be seen that for some individuals it is not that they are sheerly inarticulate, but instead that the forms of articulacy that are acceptable and which are commonly recognised do not permit others to articulate what they are trying to communicate. The possible limitations that this may place on the transmission of information between the subjects within this study and the people they live with, and with those who support them at school therefore has the potential to be hugely significant. From this position; a willingness to understand the subjects' highly individualised communication systems, a sensitivity towards the forms in which information about themselves is articulated

and a willingness to accept these alternative forms of self expression by the subjects to those around them would appear essential.

In this study I present examples of 'transmissions' between participants and subjects that are often overlooked, misinterpreted or in some instances where both subjects and participants may not be receptive to the communication taking place in any form at all. I argue that these are still communication events even if one of the communication partners does not respond. For the subjects and participants, this may be because they are unaware that the communication has occurred, they have decided to ignore it, they are still processing it or they do not know how to respond to it. For both parties, this may be because the form of communication each is using lies within a highly individualised form of response that requires significant understanding and insight into – before any meaning can be considered.

It has been suggested that one feature of autism is that it is often associated with a range of difficulties in making sense of incoming information, combined with a range of difficulties in getting information over to others, and that the difficulties with getting information across to others can be of at least two kinds – a lack of awareness of the need to communicate and difficulties with the actual means of communicating information (Clements & Zarkowska 2000). Ballan (2011) states that a parent's perceptions of a child's behaviours and comprehension tend to be associated with the likelihood that communication does in fact occur in some form: a communicative activity will occur which will require the parent to decode and make sense of what is being imparted to them by their child. This positions the parent in the role of a tape machine always on record, always receptive and always vigilant and watching. Is this the case? Who is to say what action or behaviour is the dominant communicative act? This is an interesting point, as within this statement there appears to be a clear expectation that a transmission of information will take place in some way, and that presumably this communication will be jointly accessible and in some way understandable for both parties.

Communication is also perceived as a critical basis for a range of other skills, including social skills and interaction, with level of language competence seen as a major predictor of general performance and long term outcomes (Hayward and Saunders 201). An alternative position on this statement of course is that the incoming information presented by people with highly

individualised forms of articulacy also needs to be made sense of by those around them. The primary obstacle for the subjects within this study may therefore not lay in the difficulties they have encountered in getting information about themselves over to those around them, but in the efficient interpretation by others of the content and the form in which it has been transmitted.

Within this study the role that communication played between the subjects and the participants was a constantly recurring theme throughout the data and was found within all of the eight fractions. However, on analysis five of the eight fractions were found to have significantly more examples of some form of direct transmission of information between the subjects and the participants. The function of these types of transmissions/communications was seen as intentional, directly related to changes the participants linked to adolescence and wholly new in origin.

These five fractions in which examples of communication issues were most commonly located were: Projects (Activities); Discourse (Use of language); Mood as atmosphere (The feeling tone of any given situation); Embodiment (Physical & emotional feelings); Sociality (Relationships with others). Collected within these five fractions were clear indications of different forms of communication to those seen in pre-adolescence, taking place between the subjects and the participants, albeit in forms that were not always typical. Pre-adolescent communication had been described by the participants as mainly focussing on 'twiddlers' [therapeutic aids that help children with autism to calm down, self regulate and engage], food, favourite toys, sensory experiences, sensory play. Generally, experiences that the parents and staff knew well, were in control of and situations that were presented to the subjects instead of ones that they had decided were of importance for themselves. During this adolescent phase communication appeared to centre around changes in relationships, changing bodies, sexual[ised] identity, other people's bodies, control over access to spaces.

Generally the transmission of material from subjects to participants was found to be

presented in highly individual ways and required further analysis in order to locate the individual forms of communication that the subjects were presenting to those around them.

7:3 Sexuality and Communication

The Sexuality Information and Education Council of the United States (2012) has made the suggestion that specifically parent-child sexuality communication should where possible be an ongoing, bi-directional process which begins in early life and which continues into early adulthood. However, research has shown that many parents of young adults with autism are uncertain about how and when to cover sexuality with them, and what sexuality-related topics they should cover (Nichols and Blakely-Smith 2009; Ballan 2011). A later study appears to show that parents of young people on the autism spectrum are uncertain about how to best communicate about sex and are unsure about which topics to discuss (Holmes and Himle 2014). From these delicate positions some interesting questions arise, for example; if they do exist what are these 'topics'? Who would decide what the content of the topics would be? In what way would these topics be approached? How would the young person communicate what they required back to those around them, if they were unable to use typical forms of language? And if it did occur how would this bi-directionality be developed, maintained and refined?

Nichols and Blakely-Smith (2009) have described how many parents of children with autism report that they are uncertain about what the meaning of healthy sexuality represents for them, and do not feel supported in their efforts to provide effective sexuality education. Indeed, at least one study that was able to gain the views of a group of young people with autism who were able to articulate their experiences, found that they had learned about most sexuality topics by themselves. Following up interviews carried out with a group of parents who had children on the autism spectrum, it was also found that these parents were concerned that what they perceived as 'non-sexual' and 'sexual' were misunderstood and stigmatised (Mehzabin and Stokes 2011). Autism, it has been suggested, has uniquely stigmatising aspects within it, because of the extremely disruptive nature of certain autistic symptoms [sic], the normal [sic] physical appearance of autistic children, and the lack of public knowledge and understanding regarding the nature of autism. The findings of a qualitative study carried out in 1993 with parents of thirty two children with autism found that most parents perceived themselves to be stigmatised by their child's condition (Gray 1993). However, It appears clear from the reports of caregivers, and through direct interviews with young people on the autism spectrum that both high and low functioning [sic] individuals are

both aware of and interested in sexuality issues, and that this population do engage in a variety of sexual behaviours (Gabriels and Hill 2007). This final position, of a developing sexuality being a relevant feature of the lives of people with autism, is borne out through the data collected over the duration of this research project and is evidenced throughout this study.

In this chapter I am suggesting that by reframing the behaviours that the participants have described in the extracts as potentially communicative acts, we can perhaps develop new understandings around the ways in which differently articulate individuals convey information about themselves, perhaps about their sexual selves. From this position we might present alternative interpretations, ones that may point towards some of the ways in which the subjects are attempting to present certain characteristics of their developing sexual identities during adolescence, and their attempts towards individual action and outcomes within their own lives.

I present this in the form of an exploration of the different individual forms of communication that were felt by the participants to have been used by the subjects, how they were seen as indicating changes during adolescence quite distinct to the forms of communication that had previously been seen in pre-adolescence. I examine how these communicative acts were interpreted and what the outcomes of this communication/ interpretation experience were for participants and subjects alike.

The subjects within this study articulate their experiences differently and use a range of methods in which to communicate which do not rely on spoken language. Because this experience of communicating with others is by definition highly personalised, and the content of the communication typically individual to each of the subjects, any similarities or parallels are of interest. The participants within this study reported on a series of incidents that they believed were directly related to changes that had started to occur during adolescence, and which for them indicated ways in which the subjects were attempting to transmit information about their developing identities during this developmental phase.

In the following extracts some examples of the different ways in which the subjects have communicated these changes to those around them are explored. From the information

collected across the five fractions listed above, communication was shown to be directly related to a recurring series of sub themes, which are:

- Communication related to the need for a private space required for private touching.
- Communication experienced as a change in mood, tone or atmosphere.
- Communication expressed through behaviours that may present challenge.

7:4 Communication: Private space and private touching

In this section I will be exploring situations that have involved different forms of concealed touching which may be viewed as masturbation and the type of communication and negotiation of private space that took place between the participants and the subjects.

Within this study masturbation will be defined as any form of bodily exploration that is interpreted as acting as a means towards some form of physical or emotional arousal, it may not necessarily entail touching of the genitals, and the exact form that it takes may remain unknown, as it is by definition an act that is often carried out in private. Many males begin masturbating between ages thirteen and fifteen (Strong, et al., 2005), and while this statistic relates to research carried out on what may described as typically developing adolescents, it also applies equally to individuals on the autism spectrum. There is no evidence to suggest that sexual feelings and the needs of individuals on the autism spectrum are any different than the rest of the population (Gravelle et al 1998). In this study the participants have generally all linked what they describe as attempts at masturbation to the use of a private space, or to a clear observable communicative response around the invasion of what may have been demarcated as a private or concealed zone by the subjects. Four out of the five subjects were interpreted by the parent participants as being seen to communicate that they required privacy in some form expressly in order to masturbate. The other subject was described by his carer as requiring private space, but it was not felt by this particular participant that he was using this space specifically to masturbate in.

What follows are the accounts of two parents and their interpretations of the ways in which they feel their sons have articulated their positions to them in relation to private space and

how they wish to use it. In this first extract the subject's mother describes at great length her own understanding around what she feels masturbation may represent for her son, and some of the issues she feels it presents for him, specifically around his need to be understood and the way in which she can make sense of the behaviours he presents. Behaviours that she clearly views as her son's attempts at transmitting what his current situation is to those around him.

Extract 1: 'I think it [masturbation] vents off the steam, and I think...yeah...otherwise he wouldn't engage in it. So, yeah I feel that he feels that that needs to be done and that this is the route to get there, so really he's achieving the aim that he is trying to achieve, 'I need to let off some steam', 'I need to ejaculate', 'I need to touch myself', 'I need to feel ok', 'I need to release'. I think it makes him feel that he has achieved a sense of release. Cos there's no doubt that Chris has got stresses, you know with regard to being understood and with me understanding him, and his frustrations and all the rest of it. Trying to talk and not being able to form the words, trying to sing but not being able to form the lyrics, you know...so there's got to be some kind of pent up feeling and every so often – if this is his release – then I think that he feels - 'yeah great" [Transcript 8: Parent C / Subject Chris].

In this extract the mother is presenting a range of alternative outcomes that she feels are being requested by her son; 'I need to ejaculate', 'I need to touch myself', 'I need to feel ok', 'I need to release', all based around her assumption that her son's tension can be released in some way through masturbation. She feels this emanates from her son's central position, which is that of someone who is not being understood and who is aware that he is outside of some form of shared spoken exchange that he cannot take part in, and which frustrates him. The position adopted by the subject's mother as an advocate for what she believes her son is trying to communicate is firm, and her interpretations positively assert and promote his own personal exploration of his body, and she is providing an ongoing unfolding narrative based around what she believes is occurring for him. In this extract the mother appears to be telling her son's story within her own story: she is using the personal pronoun 'I' for herself and combining it with what she describes as her son's voice through the repeated phrase of 'I need too'. In doing so, she provides his voice through her voice. This was the way in which

this participant spoke about, spoke for and spoke as her son throughout the study; and as a researcher it was very powerful to listen to.

Key points: The subject's mother views masturbation as a positive outcome for her son and she is wholly supportive of his attempts at doing it. She links masturbation with his levels of stress and with his frustration around his attempts at communication being misunderstood, and with his mother not being able to efficiently decode what he is trying to transmit to her. She describes a situation where her son is aware that he cannot use spoken language efficiently, where he is 'trying to talk and not being able to form the words, trying to sing but not being able to form the lyrics' as a significant factor in his frustration, and she feels that masturbation assists him in gaining some form of resolution to this situation. In this extract the communication from the subject appears to be presented in the form of a hidden story that is interpreted and presented by the parent, who is placed in the role of acting as advocate or enabler/facilitator. The mother positions herself as the advocate to describe both herself and her son's positions, placing significant emphasis on her interpretation of the effects on her son of not being able to use spoken language. She feels that masturbation acts as both his release and as a form of communication, in that it acts as his transmission of stress and tension about his position as someone who cannot communicate efficiently what he needs, to those around. It could be argued that in effect the subject's mother has become his mouth piece and her interpretation of his behaviour has become something akin to a form of spoken vocabulary from him, interpreted and delivered through his parent.

Taking this position of advocate and enabler/facilitator is also clearly evident in the two following extracts below, which provide two separate accounts from one participant of the way in which the subject [Arran] and his mother appear to be effectively negotiating what [he] the subject requires from his mother, which is 'private space or private time' through the use of 'eye gaze' and 'body position' as a means of communication.

Extract 2 "I have actually walked into the [bed]room, when he has had the cover up hiding whatever he is doing, with just his head peeping out, and he'll just look right at me - and you can tell he's having private time. He kind of just stares kind of blank like he knows he's been caught." [Transcript 2: Parent E / Subject Arran].

Extract 3 "If he looks like he wants to stay in the room longer, he'll just shoot me a look that means - could you please leave me alone. With Arran it's all in the eyes, we look at his eyes and we know exactly what he wants." [Transcript 3: Parent E / Subject Arran].

In the first extract the subject has the bed cover held over his body concealing what the mother believed was her sons attempt at masturbation, while at the same time looking out for anyone entering his private space in order that he is not discovered. In this instance the mother has expressed that she feels that her son has presented some form of internalised sense of embarrassment or shame about what he feels she believes he is doing [masturbating]. The inference taken by the mother from the communication between them both is that her son was articulating 'I require privacy' or 'I am attempting to explore my body away from the gaze of others', articulated through three communicative actions. First, intentional concealment: I am covering up what I am doing. Second, cautious watchfulness: I am watching for someone to come into my private space. Third, eye contact combined with facial expression and body positioning. The origin of where this sense of masturbation as a private act came from was unknown to the mother of the subject, but she commented that she felt that it had started to be something he naturally engaged in as he was growing up.

In this instance the participant acted according to what she believed her son was communicating, and the two outcomes were that the subject received the privacy he appeared to require and was provided with more time to continue doing what he was doing.

Key points: In this case the subject's concept of what a private space represents is strengthened, in that it is a space that can be controlled by the subject himself, one in which he is not observable and one that he is alone in. The subject's mother has strengthened a position of trust between herself and her son, as she has negotiated with her son a form of communication that enables him to have control over his body and his environment and one that enables him to be a sexual being and to explore his body in any way he wishes. Information between son and mother has been shared and acted on, bi-directionality has been maintained, information has been efficiently transmitted and decoded and the subject has been able to do what he wanted to do, and is in control of the situation him and his mother have developed between them.

In both extracts it is clear that the subject's mother is developing a new understanding around what her son's room may now represent for him, and that her interpretation is that his room may now potentially be used for masturbation. She uses the phrase 'shoots me a look' and 'he'll just look right at me' in the extracts above to indicate that she has interpreted this tactical use of eye contact as him remaining in a position where he can see how much scrutiny of what he is doing is taking place during this private time. She believes he does this in order that if or when he is observed he can provide the correct 'eye gaze' response, which the mother interprets as – 'could you please leave me alone' or – 'can you please leave my private space because I am exploring my body'.

The use of eye gaze in combination with a presumed expectation from the subject that the mother will be able to efficiently interpret the transmission of information about his activity, is clearly evidenced in these two extracts. The subject uses his physical position [hidden] and reaction [conveyed by eye contact] to his mother entering his bedroom, two communication techniques that his mother is positive about and wholly receptive towards. There is evidence here to show how within this communication, the power lies really with the recipient. If the recipient refuses to acknowledge that a communication has taken place then the initiator is left powerless.

Key Points: in these two extracts, the subject's concept of privacy, of being provided with time alone and unobserved, is positively developed and sensitively managed. The mother feels that eye gaze is used by the subject as a means of communication, and she efficiently interprets what she believes her son is trying to convey to her. It could be argued that how receptive her son is to her communication back to him, may only be measured by the strength of belief he develops in his own ability in being understood by those key communication partners around him.

This strategic use of eye gaze as a means to gain and use shared attention can be found in the research of Mundy, Sigman et al (1986), who carried out an analysis of observations of a group of children with autism looking into some of the different forms of non-verbal communication they used. Through their research they found that there were different categories of communicative behaviours, and that within the social interaction category they found the emphasis was on behaviours that were used to elicit or respond to attention towards

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themselves. When indicating, they found that the emphasis was seen to be on behaviours including the use of 'eye contact' that were used to direct attention towards an object or event, thus establishing a common focus of attention between the child and the adult. When requesting, the emphasis was on the same type of behaviours being used to seek assistance in obtaining an object or event. The children in this study were therefore seen as acting from the position of both initiator and responder, and were seen to be able to use 'eye contact' efficiently to obtain shared attention in order to bring about some form of positive change for themselves.

Alternatively, it may be the case that in extracts two and three we are observing the subject simply requesting privacy in order to withdraw and stop any further interaction. Seen from this position it could be argued that 'people with autism therefore may face a terrible dilemma. They may have to varying degrees the human drive to be with others, the deep knowledge that survival and social interaction go together. Yet they may lack real awareness of that and the tools required to effect social interaction. They may withdraw from the social world and we may be tempted to allow that to happen, to let people be - in their own worlds' (Clements and Zarkowska 2000:19). Is this a potential outcome through the situation that appears to be developing between this mother and her son? Do these two extracts describe the mother's sensitive and empowering attempts at developing opportunities for her son to have his communication requests met? Or, are the subject's attempts at withdrawal being misinterpreted? Is it in fact even necessary for the subject's request for privacy to be viewed as something counterproductive and as a situation which could lead to further isolation?

The positions of both of the mothers in these extracts above have within them an interpretive or even illuminative role, as they are the negotiators and the expert guides translating the communication of their sons. Or, is it the case that all of these potential interpretations remain available and open for negotiation in some form at all times, and that the process of interpretation and analysis continues fluidly always changing meaning - always open to new readings.

The positive and negative aspects of this developing situation may always be features of the lives of the mother and son, who may be fixed in a continual state of negotiation and re-negotiation, interpretation and reinterpretation that will play out over time. Or, is it the case

that what has been captured is an efficient interpretation of a subtle communication from son to mother that culminates in mutually negotiated seclusion for the subject, where both parties experience validation about their roles as efficient communicators/ interpreters. Gaining a valid and workable interpretation of the communication between subject and participant and a sense of 'tuning in' is clearly observable in these extracts, and arguably the mothers of these two young men are trying to locate the mood and feeling tone of the situations their sons are in. This reading and decoding of the mood or atmosphere between subjects and participants was clearly located within the data and is worthy of further examination.

7:5 Communication: Mood, tone and atmosphere.

The existence of mood, tone and atmosphere as potentially both a discreet and fluid interconnected fraction/state was added by Ashworth (2003), and it has been described as something that is in some sense more than affect or emotion, something that is intangible that is woven into our perception, into our bodily being and into the way in which we experience the world (Finlay 2011). This additional fraction of 'mood-ness' is what I now want to explore in more detail, as I have located within the descriptions found within the transcripts, depictions of it that appear to bear out this often intangible feature of communication from the subjects to those around them.

Through my analysis of the data what became available was evidence of subtle or gross changes in mood or atmosphere reported by the participants. These changes were generally identified by the use of terms such as 'tense' or 'tension' or in descriptions of abrupt changes in mood that were not easily defined. The participants described changes in the facial expressions of the subjects, tightness in their facial features, fixed apprehensive postures or simply just a difficult to describe feeling of apprehension or rigidity around the subjects. Within the available literature the use of mood as an intentional communication tool is not widely reported on. A significant difficulty with this literature is that no studies have attempted to differentiate anxiety/mood problems for people on the autism spectrum; the suggestion being that, anxiety and mood are hard to measure in adolescents with autism, particularly for those with very limited verbal skills [Kim and Szatmar et al 2000]. Arguably unpredictable changes are a typical part of life for all young people, but teenagers on the

autism spectrum can appear to have more frequent or more severe mood swings than typically developing teenagers (raisingchildren.net.au 2016). If this is indeed the case it may be necessary to develop a different approach to extract and document the signs of mood [dis]orders [sic] for people with autism (Lainhart and Folstein 1994). In the following extracts the ways in which mood, feeling tone and atmosphere appear to have been used by the subjects as a form of transmitting information about their current position, is explored.

In this following extract the subject's mother describes how she believes a feeling of tension has been developed around her son's need for a private space, a situation which has presented the family with the opportunity to reconsider how they approach a previously shared space that the subject is now marking off as private. The mother does not mention masturbation in any way in the interview, and simply states that he requires 'private time'.

Extract 4 "He never needed his room for private time before, he shared it with his cousin, and there was no problem, but now he gets very tense if you even go near his bedroom door, we try not to go up there [to his bedroom] anymore. And there are times when you could cut the atmosphere on that landing with a knife." [Transcript 7: Parent D / Subject Mahmud].

In this extract the mother's interpretation of her son's communication, that he has a need for privacy, has led to the area of the house where her son sleeps and spends a lot of his time becoming a zone that is restricted for other family members. She views the change that has taken place as problematic and describes his responses to anyone going into this area as 'tense'. This has led to further withdrawal by the subject and any form of negotiation around this space has been difficult to develop. Negotiating access into and around this space has now become a considerable issue for both the subject and the family. Here I am arguing that there is evidence that the use of mood and atmosphere as a means by which the subject has transmitted his requirements around the use of a key space in the home, need to be recognised as a discreet mode of communication.

Recognition of the subject's communication about this space requires validation, and the required renegotiation of the space following this communication would arguably require a sensitive response. If the subject is indicating that he would prefer to withdraw into a separate space, then how will this be accommodated? This type of withdrawal may be temporary or long term, it may be a reaction to distress or feelings of vulnerability in which

the subject shuts down or closes off interaction with or consideration of others. Or it may be what Williams (2016) describes as a form of autistic encapsulation; where a range of conditions and circumstances may result in the extensively diminished ability to consider, relate to, trust or need the involvement of others. From this position the subject is wholly dependent upon how the caregiver feels about him being a sexual being - whether this will be allowed or denied. The use of withdrawal away from people into a private space which has already been reported on previously in this study, combined with the tangible sense of tension and mood change that the family now feel is evident in this extract and can be viewed as two distinct forms of communication in their own right.

Key Points: The subject's need for privacy appears to have been seen as problematic for the family; the communication from the subject to the other family members is interpreted in the form of 'tension' that the mother and the other family members now feel. This transmission of a subtle shift in the tone or mood of the interaction between the subject and the other people in the house I would argue - is the communication, and in this case it has been effective. That he had not previously required the sole use of the room he shared before would indicate a change and the interpretation from the subject's mother on how he now reacts around his room would indicate a transmission of information about what that change represents for him. Which is, that something significant has taken place for the subject that requires him to use this space in a different way than he did before.

In this fifth extract the same participant presents further evidence of this sense of unaccounted for tension that she now feels from her son.

Extract 5: "sometimes it just gets kind of like, tense around him, and there is obviously something's up, there's a tension there and he'll stay very, very still. When he's like that the atmosphere in the house changes and we are all on tenterhooks" [Transcript 7: Parent D / Subject Mahmud].

Key Points: The presence of a subtle or abrupt shift in mood or atmosphere that the mother had felt was intentionally used by her son, is again evidenced in this extract. Whether it is used intentionally by the subject or rather that this shift in mood is something which is just the outcome of the action of his caregiver clashing with the desire of the subject, is open to debate. What is real for both the subject and the family is the reaction of those around the

subject, and the sense of influence that this is having over control of spaces, people and events in the home.

What appears to be clear is that these shifts in mood state are new; that they represent something significant in terms of their communicative content and they are invariably linked in some form to either a state of stress or to some form of request, namely ['I require my own space']. In extract four the change in atmosphere created by the subject around access to his room was clearly evident for the mother. In extract five the subject's mother again reported back on what she interpreted as observable stress and tension exhibited by her son, so much so that it had led to him adopting a very fixed posture. There is evidence to show that in certain situations some people with autism can experience levels of irritability, which may be manifest as aggression, tantrums or rapidly changing moods, and that these behaviours can profoundly impair functioning and cause substantial individual and family burden [Owen and Sikitch et al 2009). In extract four one interpretation of the subject refusing to leave his room may be that he is masturbating, which may serve the purpose of releasing tension because he has no way to access areas outside of the home or other experiences that are outside of his agency. In this instance, negotiating the change in communication that is reported by this participant would require a sensitive and calm responsive approach from all involved, in order to facilitate a deeper insight into the changes that the subject appears to be undergoing.

In the following two extracts, independently of each other, one staff participant and one parent have described what they have interpreted as a feeling of tension around two of the subjects, a feeling or a shift in mood, that they felt was representative of a communicative act in itself.

Extract 6: "Lately I've noticed that his face will go to like very serious, and you can see there's a lot of tension in him, this could mean he really likes you and doesn't want you to go or - get out now! And he can change with people quickly, I've thought we were ok - when we weren't" [from notes taken staff meeting: Staff C / Chris].

In this extract the transmission of information from the subject to those around him has been interpreted by the participant as taking place in two forms; first, through a change in facial expression and second through a change in mood. In this instance the member of staff has limited their interpretations of this change in expression and mood to two possible outcomes;

one positive ['he really likes you and doesn't want you to go'] and one negative ['get out now'], which of course by definition would lead to a positive outcome for the subject if that interpretation was correct. Her interpretation of the meaning behind a change in his facial expression continues along similar lines within this dual outcome scenario, with her description of a state existing between them now being either 'Ok' or 'Not Ok'.

Extract 7: "Gerry can come in and he is tight, his face is tight and you feel the mood around him, that means 'I need my space' simple as that, we all know that, give him some space, it's obvious if you know him" [from notes taken: Staff N / Gerry].

What is identified in this extract is the way in which it is felt by this member of staff that the subject has used a change in the mood around themselves in combination with a change in facial expression to convey what they require at that given moment. This participant also states that this has been accepted by everyone who knows him, and that these other staff members have gained a clear understanding of what this apparent attempt at communication represents.

Key Points: In the first of these extracts the subject Chris's mother interprets the change in his facial expression as a response that she feels he is using to communicate how he is feeling, and as a way to indicate that he is reacting either positively or negatively towards someone, or that he requires privacy. In this extract a number of things are evident; the participant feels that the mood between the subject and those around him can change abruptly, this change in mood is interpreted as having some form of direct impact on the subject, and the meaning within this change is not always clear and can be potentially misinterpreted. In extracts four and five the subject's mother describes her interpretation of a 'tension' around her son that is [for her] challenging to understand and potentially difficult to negotiate. Mahmud's mother reports what she describes as an intentional shift in the atmosphere or mood around her son, a change that she feels represents some form of tension and one that has a direct impact on the subject himself - 'he becomes very still'. The parent and the two members of staff have independently described situations where they have experienced a change in mood around the subjects, occasionally combined with other linked behaviours [change in facial expression / fixed position], and have interpreted these exchanges as something that has for them, some form of clear communicative function to it.

Within these seven extracts it is possible to see evidence of a range of communicative events occurring in different forms: The efficient use of meaningful eye gaze, withdrawal into secluded spaces, use of facial expression, use of body position all used in combination with a shift in mood or atmosphere between the subject and the people around them, that some of the participants have reported as being used instrumentally by the participants. The creation of a change in mood / atmosphere through a range of behaviours, in order to communicate the current state of being from each of the subjects to those around them.

In the final part of this chapter I will examine some of the more distinctive forms of behaviour that the participants have reported back on to see how their interpretations impact on outcomes for the subjects; how they may be linked to changes the subjects are going through and whether new meanings have emerged through the way in which these behaviours are interpreted and understood.

7:6 Communication: Expression through behaviour

Imray (2007:1) puts forward the suggestion that 'there is no such thing as behaviour without a reason, all behaviours must have a reason behind them and that reason always have a meaning. We cannot hope to understand the behaviour unless we are prepared to both try to understand and try to accept the meaning behind it. And, at the most basic level behaviours that challenge are all communications, they might be poor communications, they might be appalling communications, but they are communications none the less and probably they are the best the child can do'. Arguably, all behaviours have some form of communicative function, they may include expressing difficulties in processing information, they may be linked to issues related to unstructured time; over sensitivity or under sensitivity to sensory experiences; changes in routine; difficulties around transition between activities or physical reasons such as feeling unwell tired or hungry (NAS 2016). Positioning behaviours now being seen in adolescence as they are used by the subjects, regardless of their content, presentation or delivery in this way - as a form of communication is what I now want to explore.

In the extracts that follow I will examine a series of situations in which the participants, two members of staff and two parents, describe changes that they have witnessed in the behaviours of three of the subjects. Changes that they feel indicate attempts at self-expression made by the subjects through behaviour, around situations directly related to

their adolescence. The extracts describe behaviours that could be described as presenting some form of challenge and which are either directed towards specific people or are forms of self-injurious behaviour that the subjects have directed towards themselves. It has been suggested that a high proportion of children with autism with severe speech impairments use what could be described as challenging behaviour as a form of expressive communication (Chiang 2008), and that the recognition that challenging behaviours may well be a form of communication used when a more acceptable and effective means of expression is outside of an individual's repertoire (Thurman 1997) needs to be acknowledged.

In the following extract the subject's mother describes a behaviour directed toward others combined with Self Injurious Behaviour (SIB) directed towards the subject himself, which she feels indicates something that is occurring for her son that she is unable to clearly understand.

Extract 8: 'But now, for no reason that I can see, he will just lose it, he'll start by smacking his face and smacking his head and then he'll go for the person nearest to him, he'll just grip them and he won't or he can't let go" [Transcript 7: Parent D / Subject Mahmud]

Mahmud's mother appears to be describing three central behaviours all of which can be seen as separate communicative actions presented by her son; first, is the self-injurious behaviour towards himself ['face smacking' and 'head smacking'], second is the reaction to the person in close proximity to him ['he'll grip them'] and third, is his inability or unwillingness to let go of this person ['he won't or he can't let them go'].

Key Points: These combinations of behaviours appear to be new in that they have only started to be recognised by the family since the subject entered what could be called adolescence and its antecedents are unknown to the mother. This behaviour has the capacity for a number of potential outcomes, such as: drawing people into contact with the subject in the form of physical restraint, giving the subject space and for those around him to be nervous or uncomfortable with these behaviours. It has been suggested that children in proximity to adults who describe themselves as stressed or uncomfortable tend to react with one or more of the following behaviours: an increase in either the frequency or intensity of self stimulating rituals, more oppositional and challenging behaviour, decreased responses to requests, decreased eye contact and more neutral facial expressions (Honma, and Tanaka et al 2012). From this position it is possible to see how behaviour of this intensity can lead to the people

around the subject inadvertently reinforcing, or in some way maintaining the behaviours they are witnessing.

The following extract offers another similar interpretation of a series of different behaviours that for this staff participant are marked by the often unpredictable quality they have to them.

Extract 9: "He'll just wallop you hard, like boom right on your head and that'll mean go away cos I don't like you or you're too close, then with someone else he'll take their hand and stick it on his head, cos he likes his head massaged – but not by everyone' [from notes taken staff meeting: Staff A / Min].

In this extract the interpretation of the member of staff is that the subject appears to be communicating different outcomes that they require in two separate ways. First, using the communicative action [a hit to the head] which is interpreted by the staff participant in terms of its communicative function ['go away - because I don't like you']. Second, using the communicative action ['taking their hand and sticking it on his head'] which is interpreted in terms of its communicative function as the subject communicating that he is allowing this chosen person to touch his head, with the inference being that the subject is indicating a preference for one person over another.

Key Points: Here the subject is interacting in a way that appears to indicate their preference for one person over another. The member of staff has inferred from what they have witnessed that this is one way in which the subject selects those individuals they may feel comfortable with or rejects people they do not. Viewed in this way the subject appears to be selecting with whom he wants to be physically close to at different times but the means by which he rejects people is potentially problematic.

In this next extract the staff participant is describing the types of responses presented by the subject following a misjudged movement during an interaction.

Extract 10: "If we've got it wrong [during an interaction] he will bite his hands deep, or he will hit his head hard, no doubt about it, he'll bite himself or he will bite us - and that can be pretty scary. Sometimes he can't stop biting himself and then things just kind of escalate" [from notes taken staff meeting: Staff B / Gerry].

In the example presented above, self injurious behaviour or injury to others is the principle form of communication used by the subject to indicate how he now requires those in close proximity to him to act. Within this interpretation the behaviour may be seen as an intentional communication by the subject. Sharing close space has now become an event that requires considerable negotiation and patience and the subject appears to be providing a variety of responses to communicate this.

Key Points: Working closely with the subject may involve personal injury which could potentially lead to opportunities for the subject to do as they wish curtailed. Sensing trepidation from the staff supporting them may also lead to more instances of self injurious or confrontational behaviour towards staff.

Self injurious behaviour as it is experienced by some people with autism is also often inextricably linked to levels of arousal, and it has been suggested that a person's level of arousal is associated with different forms of self-injurious behaviour. Researchers have suggested that self-injury can act as a way to increase or decrease one's arousal level. The under-arousal theory states that some individuals function at a low level of arousal and engage in self-injury to increase their arousal level (Edelson, 1984; Baumeister & Rollings, 1976). Viewed in this way the incidents of self injurious behaviours described in these extracts could be considered an extreme form of self-stimulation (Edelson 2016). In contrast, the over-arousal theory states that some individuals may function at a very high level of arousal and that they may engage in different forms of self-injury to reduce their arousal level. That is, that the behaviour may act as a release of tension or anxiety. A reduction in arousal may be positively reinforcing, and thus, the individual may engage in self-injury more often when encountering arousal producing experiences (Romanczyk, 1986). Whether SIB is an outcome brought on by different levels of arousal is an important component feature to consider when examining what these behaviours may possibly represent. Within this study, I am suggesting that behaviours such as the ones described here have within them a communicative element which may well be a product of the types of arousal described. To reiterate Imray's point again, around what challenging forms of behaviour are – namely that all behaviours must have a reason behind them and that reason will always have a meaning - my contention is that this meaning is transmitted through the behaviour, in whatever form it is embodied or expressed.

In this final extract the subject appears to be presenting a range of different self directed physical behaviours which the parent has interpreted as representing her son's reaction to some form of transformative phase that the he is going through.

Extract 11: "Yeah he's now very active and stroking himself hard all over and grabbing himself and gripping himself, and he's changing - actually he's going through a massive change. He's growing up isn't he.' [Transcript 4: Parent A / Subject Gerry].

In this final extract the mother has interpreted the new behaviours her son is presenting: raised activity, stroking, grabbing and gripping his body as clear indications that he is undergoing some form of transformation from being a child into being an adolescent. She uses the words 'very active' in describing his exploration of himself, perhaps a type of extreme activity that she had observed before in him as a child but one that now takes on a new meaning when seen in the context of his adolescent physical self.

Key Points: The subject's mother interprets this change as manifesting itself physically and emotionally in or on the surface of the body of her son; she appears to view these new physical behaviours as signs of this change [from child to adolescent] and as her son's attempts to cope with the sensations it presents him with. Through these behaviours he is undoubtedly communicating something which has significance to him, and something that manifests itself through these behaviours. At present there are unknown elements to the complexity of this situation, but for the mother it clearly represents change and transformation in some form.

7:7 Summary

The overall focus of this study is to examine evidence of changes that are taking place for these subjects during adolescence; to explore whether potentially these changes may represent evidence of the impact of developing sexuality and to look at how these changes are interpreted and managed by those around the subjects, what meaning is attributed to these changes and the impact of that on the subjects themselves. This chapter has focussed on some of the ways in which the communication of these changes has been understood and responded to. Through this analysis it can be seen that communication is arguably the most complex of all human behaviours and one which is absolutely fundamental to an individual's

experience of identity, relationships, choice, assertion, control and emotional and self expression. Effective communication can assist in enabling an individual to develop personal identity and self-esteem, build relationships and exert a measure of control over their life (Thurman 1997). Positioned in this way, understanding alternative forms of communication may therefore also play a significant role in the way in which fledgling forms of sexuality are to be found, nurtured, given credence and supported.

In summarising what is under examination in this chapter, what appears to be clearly evidenced in the examples provided, is the critical role placed on the development of a flexible rapport between the subjects and the participants. If Communication is viewed as a two way experience, when viewed from this position the central role played by the parents and the staff close to the subjects, and their ability to apply a sensitive interpretation to the subjects' attempts at transmitting information about themselves, cannot be underplayed. Most behaviours, whether identified by others as problematic or not, are meaningful, and they are to a greater or lesser extent about meeting needs and wants (Clements and Zarkowska 2000:36).

What are captured in these extracts are the participants' interpretations of some of the different forms of communication felt to have been used by the subjects, to indicate the changes they are experiencing as they move forward into adolescence. Information rich indicators, representing each of the subject's evolving ways of being – made available to the people around them. What I am suggesting is that the subjects are presenting their experiences of transformation through their own highly personalised communication systems, on certain occasions in ways that are intentional at other times in ways which may appear unintentional. The participants are on the whole receptive to these transmissions and act as expert guides and advocates, on the whole providing a meaningful interpretation of what they observe.

Embedded within the signals transmitted by the students is I would argue vital information about; how they [the subjects] want to assert themselves, how they may be attempting to control their environments, how they are negotiating changes in the ways in which they relate to people known to them, how their bodies now feel, how they may want to explore what their body can now do, and who they are becoming. These, I would argue are all critical

features of the way in which adolescence is developed, how a burgeoning sexuality is grasped and how transformation from one type of being [child] into another type of being [adolescent] is positioned.

All of the participants involved in this study are to some extent placed in the critical role of being an advocate for these young men and interpreters of the communication they present, and through their advocacy they are tasked to consider and support these young men with the changes that they may be going though. For these young men understandings of concepts such as privacy, sexual expression, identity and self are still forming and the people positioned in these interpretive roles are therefore pivotal. As advocates of course, they bring their own personal ideas, beliefs and values to the interactive exchanges they are involved in (Tissot 2009), and this is an important issue to consider. These parents and staff are in positions of enormous control and influence over these young men, and the quality of their interpretations and the impact of their responses can be significant. One substantial finding raised within this study, available across all of the fractions, has been the presence of 'mood, tone and atmosphere' as a communication tool. These characteristics which act as a fraction in their own right have permeated all of the other fractions, and all participants have repeatedly commented on this feature of the subject's life as being of huge importance. This bears out Ashworth's notion that the fractions of the Lifeworld are indeed interconnected by nature and this also lends credence to the idea of bi-directionality raised in this section. This important finding will be discussed in more detail in Section Three of this study.

What I am suggesting has been identified within the extracts presented in this chapter, is evidence of the subjects highly personalised attempts at validating their identities and communicating their ways of being to those around them. Bakhtin (1984:287) has suggested that 'to be means to communicate, to be means to be for another, and through the other, for oneself. And that a person has no internal, sovereign territory, he/she is wholly and always on the boundary; looking inside him/herself, he/she looks into the eyes of another or with the eyes of another.' What I am suggesting is that through this process of interpretation by which often challenging forms of articulacy are given validation, the identities of the subjects emerge and become available.

This exploration of Identity formation will be the focus for the following final chapter of this data analysis section of this study and will conclude my examination of the themes identified within the data. So, in closing what has been revealed here is that our interpretations of 'typical' forms of communication may potentially be too limited in nature, and this study goes some way towards troubling the notion of humans as necessarily skilled communicators or interpreters. In the fourth and final chapter of this section I continue with this exploration of the data, with an examination of some of the ways in which the participants have reported back on the subjects' attempts around presenting their individual identities. In this chapter I draw from the preceding chapters which have acted as a platform from which to evaluate the shared experiences of the participants and the subjects, which I will argue are in so many respects wholly interconnected and interdependent on each other.

Chapter 8 Identity

8:1 Introduction

The way in which a person may represent themselves and their identity as an individual, as a separate self, is not easy to describe and the identities of disabled people are potentially even more difficult to establish, as they are typically based on the perceptions and interpretations of others. Shakespeare (1996:20) argues that 'the experience of disability as an innately negative identity can arise out of a process of socialisation, or in the context of social relations, in which impairment is the sole focus of analysis'. The concept of self is notoriously difficult to define and different notions and theories of the self have been proposed by a variety of disciplines all interpreting concepts of self and identity in various ways (Lyons and Fitzgerald 2013). Linton (1998) has suggested that a person's abilities or characteristics are in fact often wrongly determined by 'disability' and that people with disabilities as a group are inferior to non-disabled people. Kidd (2001) defines Identity as the condition of being a person and the process by which we become a person, that is, how we are constituted as subjects. So what then constitutes a disabled identity? The concept of "identity" has become both a contested and a fertile field of research and theory in recent years (Watson, 2002) and several assumptions have come into focus: first, that identity can be structured upon shared social experience; and second, that there are fixed identities of persons with disabilities and within that the self plays a significant role in the formation of identity (Murugami 2009). Disability in a socio-cultural context has been defined as 'a barrier to participation of people with impairments or chronic illnesses arising from an interaction of the impairment or illness with discriminatory attitudes, cultures, policies or institutional practices' (Booth 2000:28). It may be the case that the conception of a unitary identity, as a single form of entity, for people with disabilities is impossible (and perhaps undesirable) to codify. Rather, that disability as an identity is often a personal construction, a purposive attempt to make meaning of 'self' in the world (Johnstone 2004).

Seen in this way, the construction of identity can be conceived as a highly social, ongoing process, and for individuals with disabilities this process can be particularly challenging, given the powerful negative discourses of disability. Disability has been described as the outcome of impairment: as a form of biological determinism, because it tends to focus on physical

difference. Disabled people are therefore defined as that group of people whose bodies do not work; or who look different or act differently (Shakespeare 1996). However, from this position of rejection and negation there is the potential for empowering narratives around disabled identities to emerge, and when viewed in this way 'the disabled body, then, is not only a site of oppression but (like all forms of oppression) always contradictory and therefore full of the promise of potentiality' (Goodley 2017:89).

Unlike identities that seek to overcome or minimize disability as a concept, some disabled individuals place the notion of disability in the foreground of their identities. The placement of disability as a valued concept in identity formation has largely been the result of the shift from the medical to a social discourse on disability. Peters and Chimedza (2001:24) see disabled identity as 'the "reclaiming of the body" away from models that diminish the value of people with physical disabilities'. Goodley et al (2015:8) suggest that the lives of disabled children and young people demand us to think in ways that affirm the inherent humanness in their lives but which also allow us to consider their disruptive potential. Riddell, Baron and Wilson (2001) state that people with disabilities often have a limited range of identities to choose from because of societal labels and ascriptions. These choices, note the authors, inevitably affect the life choices and future visions of people with disabilities.

While, as can be seen in the descriptions above, there has been some attention given to the issue of identity and disability, there has been little attention paid to the process of identity construction for individuals with autism (Bagatell 2007). Gillespie and Kapp et al (2017) touches on some of the tensions around identity formation that people with autism may face, when she states that as a young person with autism; maintaining a strong and healthy sense of self-identity can be challenging, when those around [us] do not respect the way in which we choose to identify, or may expect [us] to be able to fit only the stereotypes they themselves have created in relation to who they think autistic people are. Viewed from this position, the identities of disabled people may therefore always tend to exist within the narratives of the people who live with them and who support them, and their authentic identity can lose its validity, it can often potentially remain hidden, misinterpreted, over looked or in some cases may even be missed out altogether.

In this fourth and final chapter of the data findings section of this study, I will explore some

of the different ways in which the participants in this study believe the subjects have demonstrated changes taking place within their developing identities. I will examine some of the signs / indicators available within the data that point towards highly individualised forms of 'self agency' that the subjects appeared to be using, as a means to represent who they are and what they were experiencing. I will argue that this can provide new insights into: different forms of expression around alternative modes of being and the ways in which hidden forms of identity can be revealed. I also ask whether the identities of individuals who are unable to access typical forms of communication can ever be recognised by those around them or whether these identities simply remain something that people intuitively come to know or form interpretations about - be it correctly or incorrectly. I also explore the notion that what may potentially have become available within the data is evidence of a form of combined and jointly accessible shared identity, that all recipients experience together and which is some form an ongoing experience for all actants.

Captured within the data are depictions of what the research participants believed were developing identities forming during this period of adolescence. Here are descriptions of the subjects' attempts at experimentation around what their bodies and the bodies of others now represented for them and their efforts at reaching out for new experiences, exploring different forms of self-action and self-agency and experiencing what appears to be transformation and change.

However, through my analysis of the transcripts, what quickly became apparent was that all of the participants within this study believed that to some extent the changes they had observed and described across all of the five subjects, had within them certain potentially sexualised characteristics that they assumed formed the basis for the emergence of some form of new developing sexual identity for the subjects they were describing. Whether any developments in the identities of the subjects, as they are described by the participants, have within them some type of sexualised qualities, and the ways in which a sexual identity as an entity in itself can be attributed to another, is open for debate. Never the less, what this may reveal about the ways in which identity and potential notions of sexuality are linked, and how sexual expression and forms of sexualised behaviour are interpreted, understood and acted upon is of interest to me. Having worked closely with the subjects within this study as well as other young people with similar profiles I have seen firsthand how the identities of those

unable to access language easily are arrived at. How certain behaviours that may focus on areas of the body commonly recognised as linked in some way with sexual forms of expression can quickly become labelled as 'sexualised' behaviours; and how this can affect relationships between support staff and students, families and children. I have witnessed how negative 'sexual' profiles are assembled and maintained and how that can often lead to those young people adopting new 'troubling' identities for those around them. Identities that they may not have adopted themselves, and which may well have been imposed upon them by others.

For these reasons this area of identity acquisition and designation is something that I want to explore in this chapter. Before continuing, first I will explicate how I will be using the terms 'identity' and 'sexual[ised]', and the meanings that they have within this study. This will provide transparency around any discussion about perceived changes in the identities of the subjects, and will assist in examining how connotations of sexuality have been positioned and linked to these changes, as they are identified within the data.

8:2 Identity - Selfhood

Within this study 'Identity' is seen as being something that is expressed through three separate experiences, these are self agency, self-action and sense of ownership. First, self agency: this has been described as 'the sense that I am the one who is causing or generating an action' (Gallagher 2000:15). A physical manifestation of the self is the sense of agency, or ownership of action. It has also been argued that this sense of agency is a central aspect of human self-consciousness and that it refers to the experience of oneself as the agent of one's actions (Lyons and Fitzgerald 2013). Second, action: this can be described as the process of doing something, typically to achieve an aim; the economist Ludwig Von Mieses (1949) captures this state of 'action', when he states that human action is essentially driven by the need to satisfy our own ends - in whatever form that may take. For people with autism the intention and purpose behind their own individual actions may often be difficult to decode and understand, although the meaning of the actions may for them be hugely compelling, of great significance and deeply satisfying. Third, sense of ownership: this can be described as 'the sense that I am the one who is undergoing an experience and that I am the initiator and source of the action' (Gallagher 2000:15). Acting as the initiator of the experience in this way each individual is therefore motivated to orientate themselves to do something, and this

orientation of motivation drives the underlying attitudes and goals that give rise to action—that is, it concerns the 'why' of actions (Ryan and Deci 2000).

Within this study descriptions of different forms of what have appeared to be, self-agency, orientation and self-action have been found within all of the eight fractions. These have been articulated through the ways in which the subjects have utilised or excluded certain people in their lives; through the ways in which they have presented ownership or rejection of key spaces both at home and at school; through the ways in which they have carried out highly personalised acts; and in the ways in which they have appeared to use their bodies and occasionally the bodies of others as a way in which to carry out some form of identification of who they are and what they currently represent – as a separate entity.

8:3: Sexual[isation]

It has been argued that the sexual selves, bodies, pleasures and identities of disabled people are routinely problematised, surveilled, regulated, rendered unintelligible and, in some contexts, deemed uncontrollable and in need of containment (Liddiard and Slater 2015). What makes something 'sexual' and what sexualised behaviour in itself actually is, if it is indeed anything at all, needs some form of explanation, and for this study the term sexualisation as a word in itself requires continual clarification and revisiting. In the sense that although used quite widely and seemingly identifying important social changes, it has itself rightly been criticised as being remarkably opaque (Attwood 2006; Egan & Hawkes 2008; Gill 2008; Buckingham et al. 2010). Duschinsky (2013) suggests that the term 'sexualisation' emerged as a portmanteau of the words 'sexual' and 'socialisation', with Spanier (1975:34-35) first coining this term and defining it as 'having three major components: development of gender identity; acquisition of sexual skills knowledge and values; development of sexual attitudes'. I use this quote as a means through which it may be possible to see how for people with different perhaps less normative ways of being, notions of identity let alone a 'sexual' identity can indeed be hidden, obscured and often incomprehensible to those around them. The reasons for this, I would argue, lay within the ways in which potential misunderstandings and misinterpretations can occur around the multifarious forms of self-identification that some disabled people choose to use to express their individual personas. Knowledge about how the body can operate and change as an adult may be understood differently and often

in a highly individualised form, and a set way of thinking or feeling about these changes may be experienced differently and in variance to more normative ways of understanding. This can therefore lead to a situation where alternative forms of sexual identification that emanate from the [disabled] person can become invalidated and obscured. For instance, identifying and purposefully aligning oneself with any socially constructed notion of gender may not necessarily be the typical trajectory point for people who can present with often quite singular ways of being, and with often quite diverse forms of [self]representation and [self]expression.

It may be the case that describing something as sexual has within it the essence of something linked with some form of physical arousal, or with some form of heightened state that is experienced through the body in some way. A different feeling that is brought on by the need for a certain experience, an event, a key person, a particular space, a sensation – something that is external to the individual but something that they react to. However, I would argue that it is important to guard against falling into the trap of 'sexualising' behaviours that may typically fall within that definition. Arousal may have within it a sexual element or motive, or it may not, while there may be what appears to be a directly sexual motive, including self stimulation, the behaviour could also be a means of comfort or a means of distraction, or a call for assistance in the face of some stressful circumstances (Conner 2007), even if the stress experienced by the person is directly brought on by physical arousal. Whatever the cause or the motive may be, the emphasis I would contend centres on a connection with self satisfaction of a need, in whatever form it manifests itself, even if the objective, purpose and intention of the arousal / satisfaction are unknown to the individual or even prohibited.

8:4 Fractions

The focus of this chapter would appear on the face of it to relate directly to the fraction: Selfhood (Social Identity), a category which was used within this study to group information that pointed towards the distinctive ways in which the participants believed the subjects had represented themselves as individuals. Collected within this fraction was information about who the participants believed the subjects were, how they came across to others, what it was that was distinctive about the ways in which they represented themselves, what they did and how that created an impression of who they were. However, data that indicated the

development of certain features of identity were available within all of the transcripts and across all eight of the fractions to a greater or lesser degree.

Evidence of identity formation was observed in the following fractions in a range of different ways. Sociality: especially around re-identifying in qualitatively different ways with certain family members and with significant others in their lives. Embodiment: observed through changes in the ways in which feelings were exhibited towards others, especially around what they [the subjects] may individually do 'physically' if they appeared to feel a certain way about a certain person, space, experience or event. Temporality: changes around behaviour and interaction with others linked with certain times of the day, duration of time in certain key spaces, duration of time spent isolated from others or intentionally unobserved. Spatiality: changes in the way in which spaces were used and the links these spaces appeared to have with new forms of behaviour. Projects: activities that were previously carried out with others coming to an end and being replaced with new solitary activities or private activities. New activities that were directly linked to physical exploration of their bodies; activities that were directly related to their bodies or the bodies of others. Mood as atmosphere: descriptions of changes in the mood tone around certain people and spaces. Discourse: the often highly individualised forms in which the students articulated the changes they were experiencing to those around them as they moved into adolescence.

In the following extracts some examples of the different ways in which the subjects are believed by the participants to have communicated their emerging identities to those around them are explored. From the information collected across all eight of the fractions listed above, identity / self-hood was shown to be directly related with two central sub- themes, which are:

- Identity / Selfhood observed through behaviours linked with body and spaces
- Identity / Selfhood conveyed through behaviours linked with body and of others

8:5 Identity: Body and use of space

In this first section I examine five extracts which illustrate some of the behaviours through which the research participants felt that the subjects had presented their own attempts at identification through self agency and self action. This was seen to have occurred primarily through the ways in which the subjects had begun to explore their own bodies, and through the ways in which they had appeared to use certain previously familiar spaces in different ways. The incidents described in the first three extracts are all based in the homes of the subjects, the participants are the mothers of the young men, and in these extracts they describe new behaviours that they are experiencing with their sons; behaviours which indicate both change and new challenges for them directly, around their role as primary carers.

Extract 1: "Often what he'll do now is he'll just come into our room naked and like, masturbating, and I can tell you, this is something we hadn't expected and for us if I'm honest - it has become a big big problem, and one that we are currently struggling with. Sometimes we simply don't know what to do" [Transcript 4: Parent A / subject Gerry].

In this extract the subject's mother describes a situation that is causing some considerable distress for both her and her husband; the new behaviours that her son has started to exhibit are unknown to them and are something that he has not done previously as a child. This new situation is something which clearly presents them with considerable challenges, specifically around issues related to their son's understanding of private space and what previously shared spaces may now represent for him; the open nature in which he is carrying out this exploration of his body and what it may now represent for him and the difficulties both the subject and the subject's parents face in coping with these new behaviours. The subject's sense of 'self-agency' or observable sense of personal control over what he is doing is clearly present within the mothers' description. But it may well be the case that he may not be intending to shock or be in any way provocative towards his parents, and that the effect of his actions might be outside of his agency. There is evidence to show that he has some form of subjective awareness of the action that he is exhibiting, and that his parents' sense of distress is not being registered by the subject, or that it is being processed by the subject in a way that is not easily understood by his parents.

Seen from this position it could be argued, that it is this pre-reflective awareness or implicit sense that it is he alone who is presenting this controlled bodily [action], in the way that he is presenting it [with self agency], that may indicate an attempt from the subject at presenting this new developing feature of his identity through this behaviour to those he shares familiar spaces with – namely his parents. Key factors may be at play here; proximity to each other within the home, the sense of ease that the subject evidently feels in the parents' room, the relationships that exist between the subject and his parents, a sense of stimulation or equally a sense of confusion around the parents' responses. In this situation the subject is masturbating openly, an act that it could be argued has an important role in sexual development, and as a way to learn about sexual pleasure (Fortenberry, 2013). Perhaps in this instance, the subject is sharing that pleasure with those he feels most relaxed with.

The subject's need to explore what his body can now do, in front of his parents, coupled with the removal of his clothes can be seen as a signal which may represent some form of change that he is undergoing as a young adult. In this extract the subject appears to be presenting an alternative self/body image to the one previously available to his parents, and displaying what this 'new' self/body is capable of. He is carrying out what appear to be three separate actions that emanate entirely from himself [from his body] and which are separate to the bodies of his parents. First, he is undressing in a separate space to the one his parents are in, second he is stimulating himself to arousal away from them and third he is shifting these two actions from a private space to a shared space with others known to him. This placed the parents in an extremely challenging position as this behaviour had become compulsive for the subject and at the time practically non negotiable. In this instance the parents were required to lock the door of their room for a period of time, until this behaviour had run its course. There was in time a safe conclusion to this very difficult situation for both subject and participants.

One interpretation of this situation may be that the subject appears to be aware of what his body can now do [get an erection] and what it can feel like for him [becoming aroused by touching his penis] and he is showing the people close to him what that now is. Knowing oneself and knowing one's body are closely related concepts, and in his review on body image and the self, Goldenberg (2005) argues that the acquisition of body image is not innate but, as in this situation above, acquired through experiences of one's own - and the bodies of others. Likewise, Jordan and Powell (1995) believe that a body concept develops from directly

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interacting with others, which is something that this subject is clearly doing. Arguably the subject in this extract is interacting with others [his parents] in a form wholly specific to him in a space chosen by him, and he appears to be experiencing his new body and what it is capable of through himself and through close interaction with significant others in his world. In this instance degrees of negotiation, sensitivity and patience, compliance and ultimately compromise were all outcomes for parents and subject alike.

In this situation the subject's parents were placed in a critical position of having direct impact on his fledgling identity as it expressed itself, and their responses to this expression of their son's identity need to be considered. Do they allow him to express himself in the way that he wants to in their [private] space or do they restrict this? Would this be internalised by the subject as stress for him or would he have some realisation that this behaviour is not ok in this particular space? Do they acquiesce to their son's needs and passively support this expression of his new identity, and in doing so potentially place themselves in a precarious safeguarding position? The position they adopt around restriction of access, playing an active role in supporting his actions and directing him to another space, or the adoption of a position of passive compliance are all arguably complex options, and they may all affect the identity development of their son in some form.

The parents were placed in a position where they had to see that their roles as mother and father had to change, in tempo with the changes that their son was undergoing. This is an important point, that adolescence for this young man had initiated a period of change for everyone in his world, parents, siblings and school support staff alike. When that element of change was embodied by those around him, then change became part of the development of all of those involved in his care and education.

Contained in this second extract is a description of a nightly routine that the subject's mother has always carried out since he was a baby, which is the changing of his pad during the night.

Extract 2: 'Every night now when I go in to change his pad I notice that there's stuff in it [semen], like he has been playing with himself in bed. The first time I was like, oh, now it is like all the time'. [Transcript 6: Parent B / Min].

What appears to have changed about this routine from the mother's perspective, is that the subject is now masturbating into his pad and his mother has noticed this and has positioned this new behaviour as in some way sexualised and linked in some way to him moving from childhood to adolescence. Previously when he was a child she would change his pad and it would contain faeces and urine, now as an adolescent he is autonomously masturbating to ejaculation. This evidence of his attempt at a hidden behaviour [this masturbation happens alone, in his room under his bed covers] indicates for her, an attempt by him of self agency and self action around what his body can now do that it did not do before; he is now exploring his body and the evidence of the way in which he is exploring his body is clear. She did not believe he was having nocturnal emissions [wet dreams] as this behaviour/outcome [masturbation] was continuous and typical now. This stands in stark contrast to the subject/participant scenario in the first extract and provides evidence of private exploration of the body carried out in a private space with no outward involvement required of the parent in anyway. The subject's mother does not mention this type of behaviour happening in any form throughout his day apart from at night in the privacy of his own room, and it is not reported as taking place at school during the day.

This third extract provides a description of another of the subject's attempts at utilising a private space and time spent alone in order to explore what his body is now capable of doing.

Extract 3: "Now...he just spends a lot of his time in his room, you know, touching himself, and we've just got used to that and we let him do his thing in his own time. I know what he's doing in there, he's masturbating, I see it on his sheets." [Transcript 3: Parent E / Subject Arran].

In this extract, according to the parent, the subject is undoubtedly using his body for some type of physical exploration of himself, which she feels is linked to some form of arousal. For her he has clearly identified his bedroom as the demarcated zone for that particular behaviour, a personal space where he can practise a new action [masturbation]. But what might this space actually represent for the subject? It has been suggested that - personal space is the area that individuals maintain around themselves and into which intrusion by others may cause discomfort or even anxiety. And, that people closely monitor and appropriately regulate their interpersonal space in order to obtain a comfortable distance of interaction with others (Dosey and Meisels 1969). Is this precisely what the subject in this

extract is doing? Graziano and Cooke (2006) have argued that when personal space is violated, the person may move away to reinstate the margin of safety. Thus, personal space could be seen as fundamentally a protective space, a zone of safety surrounding the body. In this extract the subject is not taking his new behaviour [masturbation] into a shared space, [as is the case for the subject in extract one] in fact the opposite is the case, he is exploring this new activity [self-action] away from the gaze of those around him, in the same way that the subject in extract two has done, in a zone that provides safety, one that is not violated and one that is protected by the family. Vlachou-Balafouti (2002:172) has commented that 'disabled children are often subjected to an intense professional gaze' and a young disabled woman interviewed by Ballard and MacDonald (1999) has described her situation as one in which she was constantly under scrutiny, stating that she could never even be 'a bit invisible'. This desire for seclusion and private exploration of the body and what it can do, is often then thwarted by the high level of scrutiny and close surveillance that many young disabled people are compelled to endure on a daily basis. Often disabled people are restricted from secluding themselves because of often unwarranted fears around what might happen if they are allowed to simply be by themselves. With enforced [observed] seclusion being often the only option for time away from others. Current legislation for SEN schools around seclusion states that 'any child, adult or young person who is placed in seclusion or isolation should be under constant observation by an appropriately qualified person' (BILD 2015:3). However, the response of staff when the young person places themselves into a secluded space remains unclear, ambiguous and open to interpretation. Where this leaves parents who may ether need to support their child to a secluded space or maintain scrutiny when they are alone, is also unclear.

In this third extract, the quality and outcomes of the experience for the parent are quite different from that of the parent in extract one. In this extract the subject's exploration of his body is occurring in a more controlled and far less invasive way, one which has presented his mother with a more passive background role to play, with far less direct challenges for her to negotiate.

The following two extracts explore this further, and describe situations that are occurring in school which involve two of the subjects. They focus on the use of certain key spaces which involve new forms of bodily exploration that have raised the significance of these locations,

from rooms in the school that had previously appeared to represent very little to places of negotiated control and power. In this extract the subject is using a space demarcated by him within his school [the toilet] for what appears to be private examination of his penis. This is a new behaviour which does not appear to have developed into physical masturbation, but which has led to changes that the staff supporting him have had to introduce into the way in which they support him in class.

Extract 4: "He'll just lock himself in there [the toilet], but sometimes we'll just have to go in, we'll knock, let him know we're gonna come in, then we'll open the door, and he'll just be staring at his penis, like frozen, he's started to do this more and more now, just going in there, and locking the door and doing that" [Transcript 7: Staff D / Subject Mahmud].

Here the subject has started to use a semi-isolated space close to the class for a new purpose, unobserved exploration of himself, which appears to potentially represent something compelling for him. This has become a recurring pattern of behaviour previously not seen by the staff supporting him. The subject goes to the toilet and locks himself in and carries out this examination of his genitalia. The staff working with the subject are then tasked with having to enter this space, occasionally with his consent but sometimes without gaining permission from him. It is apparent from the staff participant that permission to enter the space that the subject has moved into may not always be something that is easily negotiable.

A number of separate elements are available within this description. First, that the subject is now taking himself to a space that is known to him but which now appears to offer new dimensions, such as seclusion and private self examination. Second, the frequency of this behaviour is increasing, which would appear to indicate that his need to be separate from others and to have time unobserved to explore his body may now represent something hugely compelling for him. Third, options for him to negotiate with the staff supporting him around what these actions and attempts at self agency [looking at himself and removing himself from a shared environment to a secluded space] are limited, occasionally difficult to negotiate and regularly compromised. This situation raises a multitude of questions and issues around what it means to establish an identity whilst constantly policed and observed by others. How do schools manage and support students who may wish to restrict access to communal areas and shared private spaces such as communal toilets? What can staff do when restriction of

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an area in the school impacts onto other students? Where in the school is it appropriate for this subject to masturbate and is that sanctioned by the school within its SRE curriculum and Safeguarding policies?

The fifth extract in this chapter, presents another description of how one of the subjects has appeared to indicate changes in who they are through acts of self volition. This theme of 'body exploration' coupled with 'use of space', as a way in which to view changes in identity is clearly evidenced here. This extract presents a description of some of the tensions that exist both for the subject and the staff supporting him at school, around the way in which a space previously familiar to the subject now represents a zone for new forms of body exploration.

Extract 5: "Now, he will go into the cut out room and play with himself and you know what sometimes we can't get him out of there, and when we try he gets very stressed, it's a nightmare. Some people won't even try to get him out, they're scared." [Transcript 8: Staff F / Gerry].

In this extract the subject is clearly presenting his attempt at self agency through moving into a space familiar to him for a new action [body touching / masturbation]. The staff supporting him have interpreted the development of this behaviour as a compulsive form of self-expression, which has on occasion entailed them having to safely remove him from the space he has chosen. From the interview it was clear that the staff were not pathologising this behaviour in anyway, but were simply describing the frequency, duration and impact it had on the way they supported the subject and what they felt was happening for him.

Removal of the subject from this space has led to stress for the subject and this has led to stress within the team supporting the subject. There is within this extract a clearly irresolvable element, as the subject is not able to negotiate around entrance to his chosen space of safety and the staff supporting him appear to have a fixed position around how long he can reasonably spend in the space he has chosen to be in. There is an impasse here, with evidence of the need for some more work to be done around the way in which this space is negotiated and how sensitive intervention can be developed. This may assist in addressing the subject's required time for unobserved exploration of their body, which is currently limited and with control residing out of the subject's influence.

This raises important questions around who is in control of the available space and the time spent in it? How is the concept of a negotiated amount of time in this space being developed? And, what is actually happening that needs to be controlled, if it does in fact require any form of control at all.

Key Points: Available within these five extracts are descriptions of some of the individual ways in which the subjects are exploring, observing and representing their bodies in the spaces which are familiar and available to them. We have descriptions of open displays of body exploration taking place in a shared space that had previously represented what was arguably a private zone for parents, in contrast with more concealed and private approaches to personal touching and body examination that take place away from others, with the negotiation of these spaces happening in a variety of different ways.

Taken on an individual basis each of the subject's attempts at self-agency and self-action as a means in which to directly identify themselves as who they are, are clearly observable within these extracts. The profiles that are captured within the extracts are to some extent highly idiosyncratic but do have within them certain commonalities;

- All of the subjects are actively engaged in new behaviours that staff and parents have not seen before.
- Familiar spaces are being used in new ways some of which present with challenges for both subject and participants.
- All of the subjects are carrying out an exploration of their bodies in some form.
- New narratives are evolving around the negotiation of duration, space and behaviour.
- Subjects and participants alike are developing new understandings around how to be with each other.

Seen from the position of the subjects this may raise a number of issues, such as: What is my body capable of doing now that it could not do previously? Can my exploration or expression of this change take place in spaces that I had previously shared with others? What does solitary time spent exploring my body mean to me now that it did not before? Who am I now that I wasn't before?

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Importantly it needs to be borne in mind that the forms in which these issues are articulated by each of the subjects may be difficult to establish and not always easy to respond to, as understanding concrete concepts of what an appropriate space is and what an appropriate touch is are unquestionably complex challenges for the subjects within this study.

8:6 Identity: The bodies of others

Where the first section of this chapter has focused on some of the different ways in which the subjects identified themselves through their own bodies, this next section examines how the subjects have shifted the emphasis from their own bodies, to the bodies of those around them. In the following five extracts, different forms of objectification of others are described which place the subjects' projection of their identity onto other individuals. In this first extract the subject has begun to cast his brother as an object of interest in a way that he had not previously done before, and in a way that is causing consternation for his mother.

Extract 6: "His brother's feet have become the be all and end all of his life, and he is always trying to get to them somehow, his brother's aware of it and we joke about it, but for Chris it's very real" [Transcript 8: Parent C / Chris].

Here the subject has developed a new compulsion towards his brother's feet, to the extent that his brother's room has had to have a lock put onto it, in order to stop the subject from going in during the night to touch his brother [on his feet] for what his mother believes is some form of sexual gratification. This had led to a situation of considerable stress for both the subject and for the family, and a clear strategy for working out a positive outcome for all involved had proved difficult to find. Different mechanisms underlying these types of compulsive behaviours have been suggested, and these range across: a lack of social insight and skills, limited empathy, limited understanding of social information or social awareness, a lack of inhibition and knowledge, but also preoccupations, sensory preferences, reduced emotion recognition, persistent repetitive and stereotyped behaviours. (Hart-Kerkhoffs et al., 2009; Haracopos & Pedersen., 1992 Hellemans et al., 2002; Nichols & Blakeley-Smith, 2009; Stokes et al., 2007).

Exploring the same type of situation raised in extract six, this next example describes how the subject has started to touch a known member of staff inappropriately, a behaviour that he

has not ever exhibited up until quite recently and one that he is now beginning to do more and more.

Extract 7: "Mahmud has grabbed my boobs a few times, he will look at me, then my boobs, then squeeze them, now that's something he didn't used to do before and he knows he shouldn't. Sometimes if I'm in the room with him I know all he wants to do is touch me." [Transcript 5: Staff F / subject Mahmud].

In this extract the subject has started to initiate contact with a member of staff in his class in an inappropriate way; previous to this their relationship with each other had always been calm and reciprocal with no unacceptable touching or experiences that could be described as inappropriate. From the description presented by the participant she clearly feels that there is some sense of purpose and intention to the action. She also describes a sense of 'knowing' or 'awareness' from the subject, which may indicate that he has some sense of understanding around what he is doing, and that his actions may in some way be prohibited or unacceptable.

Evidence of this constant compulsion towards a new [inappropriate] form of contact with a familiar person well known to the subject is also available in this next extract.

Extract 8: 'I've seen Chris look at me and sometimes he'll put his hand out as I go by just to make contact with me [touching his mothers legs], and I'll have to give him a look to say – don't even try it mate! Cos I know what he's thinking.' [Transcript 8: Parent C / Chris].

Here the subject's mother describes her son's tentative attempts towards making some type of new physical contact with her, a form of touch that had previously not existed in the way that the mother describes it as taking place for her now. She is quick to draw a barrier around this behaviour, which she does by simply shifting the tone of her connection with him through a subtle glance, which from her description appears to be effective. The way in which the mother is represented by the subject is a critical factor here, as she now appears to have a dual role; as 'an arousing presence' and as 'an authority figure'.

Is it the case that in extracts seven and eight we can find evidence of the subjects beginning to re-identify with people already known to them in a completely different way, a situation that has already been evidenced in previous chapters within this section. These extracts provide evidence of some potentially new form of objectification towards people previously

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known to the two subjects, and in both cases the participants involved believed there to be some form of sexual element to the behaviours that they were witnessing. The separate aspects of the behaviours were described as sexualised by both of the participants as they felt that they were clearly linked to body area [breasts] in extract seven and intention [objectification for some form of sexual gratification] in extract eight.

The final two extracts of this section continue with this theme of objectifying people as a form of stimulation, with descriptions of situations where the participants have felt that the subjects have become aroused by a significant person coming into and sharing their space.

Extract 9: 'he likes girls, he changes when his brother brings girls home, it's exciting for him he gets excited you can see it in his face' [Transcript 4: Parent A / Gerry].

In this extract the mother describes what she feels is a clear reaction to girls coming into her son's space at home. Further on in the interview the parent describes how this is a new feature to her son's behaviour that the family had not previously seen before. This recognition of other people as a stimulus is borne out in the research of Dewinter (2016), which highlights certain behavioural and information processing characteristics that are felt to be linked with certain features of autism, such as specific sensory interests (e.g., interest in specific aspects such as hair, a hypersensitivity towards touching, compulsiveness) which this research suggested may directly influence sexual[ised] experience and behaviour. Whether this is the case, or whether people with autism can simply be attracted to or interested in other people for reasons that lay outside of their autism is an interesting point, and something that I will return to in section three of this study to examine in more detail.

This final extract presents a description of a situation whereby one of the subject's has developed a compulsion for another student, to the extent that it has become a defining feature of the way that the staff now work in the classroom.

Extract 10: "he is obsessive about M to the point that we have to work around it in the class all of the time throughout the day really" [Transcript 2: Staff A / Chris].

In this example the subject has started to act compulsively towards one of the students in his class, constantly trying to be close to this student, becoming stressed when the student leaves the room or when he is separated [by staff] from the subject. Preparing for any type of

disconnection from the time spent with the other student is a challenge for the subject and for the staff supporting the subject, who are in a constant position of safe guarding the student and sensitively negotiating the transition away from the student for the subject.

Key Points: This change in the subject's way of interacting with this student has become a critical feature of their identity and how they are described by staff working with them. This is a new behaviour and one that the subject had never previously exhibited before, or at least not with this intensity. This blog entry from a young woman with autism captures how this overpowering obsession with people can become all consuming and can act as a way in which to define oneself:

> 'I have always had people based obsessions, I get fixated
> on certain people, and I want to be like them, to emulate
> them, and I can't stop thinking about them. I lack a sense
> of self and live a vicarious existence. I live through other
> people and take on their interests as my own. I cannot build
> my own sense of meaning and so my sense of reality is very
> fragile and easily broken" [AAA website 2015]

Could it be the case that the subject in extract ten is living vicariously through the other student in the class, and that their sense of meaning is moving through a phase of change brought on by adolescence? Does the other student's identity and what they represent for the subject provide new meaning for the subject? Is that why this subject is so compelled to be with them all of the time and cannot bear to be apart? Or is the subject sharing the identity of the student in some way simply by their identification with them?

8:7 Shared identity

In extract seven and eight there is evidence of an indication of another subtler connection between the subjects and the members of staff, a perceptible acceptance or recognition of each other that acts as a bond between them. When the participant in extract eight speaks of 'giving a glance to the subject' it is used as an acknowledgment between them of what type of negotiated outcome may be available, because they know each other well and between the two of them there is a shared story. When the participant in extract seven speaks of 'the subject knowing he shouldn't' again it is delivered as if they know each other, that is that they share knowledge of each other, some of it no doubt hidden - some of it known. But what is in

evidence here is a quick understated accessing of a form of shared experience that exists between them both, but one which does not reside in either, one that relates to them both; an identity that has developed concurrently to their own personal identities. I would argue that this is a form of super-ordinate identity that has within it objectives, sometimes overt and visible, occasionally hidden and masked, but which are part of the interconnected identity that can develop between staff and their students and between parents and their children.

This attitude asks those people who are in positions where they are tasked to support young people with different ways of being and alternative forms of articulating, to challenge their understanding and to consider, who am I and who are you, and from that who are we together?

Key points: This section explored descriptions of what appear to be, from the position of the subjects, meaningful attempts at contact with others, and attempts at identification of themselves as independent actants. However the form in which these attempts at contact occurred and the people chosen as the object of the contact presented challenges for both the chooser and the chosen. The type of touching described by the participants in extracts six, seven and eight were deemed by the participants as sexual in content and inappropriate. It has been suggested that adolescents positioned on the autism spectrum may indeed exhibit challenging often inappropriate behaviours during puberty, and that they may experience hormonal changes and sexual curiosity during this time (Bell and Shea 2012). Also, from within this group frequently reported forms of inappropriate sexual behaviours include touching self, touching others, masturbation in public, and disrobing occur (Haracopos & Peedersen, 1992; Ruble & Dalrymple, 1993).

Safeguarding around the possible objectification of parents, family members, staff, and students is of paramount importance here, and presents very real challenges to all of those involved in supporting young people such as the subjects within this study, during the shift between childhood and adolescence. However, what also needs to be considered is the form of support and ongoing provision that is required in order to provide the subjects with a positive sense of their new delicate fledgling identities. From what has become available within the extracts it appears to be critical that their attempts at contact and experimentation with stepping out of their safety zones should not be demonised and closed down. These

attempts at exploration of what others can represent and what people already known to the subjects may represent as they change and develop into adults, can be seen as part of their growth as an individual, and part of their own attempts towards their own individual forms of identity formation.

Whether they have developed identities defined by their autism or identities outside of that label as individuals in their own right is in some ways unknowable, as these labels will only assist in categorising and limiting what the future holds. Johnstone (2004) argues that Identity has a wide range of incarnations, in that it can be ascribed by another and thus delimiting; or it can be self-ascribed and empowering. It has been suggested that 'people with labels of profound intellectual disabilities offer us exciting new ways of thinking about our humanness in relation to interdependence, mutuality and interconnection'(Goodley, 2014:2). The lives of disabled children and young people therefore demand us to think in ways that affirm the inherent humanness in their lives but also allow us to consider their disruptive potential (Goodley, Runswick & Liddiard 2015). The impact of these labels and how they ascribed identities, and the extent to which these link with ideas of disability; how they are able to carry within them a notion of deficit or inadequacy in terms of what the identity of a human may represent - is clearly a powerful outcome. However, this also highlights a position of friction and potentially even of resistance and indicates towards where the challenges for those in positions of strategic support both around the family and within the school are to be found. Those in positions of support may therefore need to question their own roles in the construction, development and nurturing of these delicate new identities.

8:8 Summary

So, with these issues in mind I pose a series of questions. Is Identity something that we adopt for ourselves, or is it something conferred on to us externally? (Arnold 2016). Is it possible that the subjects within this study have at their disposal multiple identities for different settings, and that their autistic identity is simply just one of them? Or, is identity to be defined as an ongoing accumulation of self-actioned outcomes and concurrent consequences and effects? Brown (2011) suggests that autism is an edifying and meaningful component of a person's identity, and that it defines the ways in which an individual experiences and understands the world around him or her, and that it is all-pervasive.

Within these extracts there are representations of Identity presented through the bodies of the subjects or via the bodies of others, by touch or through the rejection of touch, or by highly individualised behaviours such as the objectification of parts of their [the subjects] own bodies or the bodies of people known to the subjects. Identity I am suggesting may therefore be developed and extended through: interaction with others; through continued interconnection with others; with what all of the participants categorically described as additional highly individualised sexualised components. Through focussing on different depictions of their own bodies; hidden, naked, entering private spaces, entering shared spaces, in states of distress and calm. Identity is presented through recurring patterns of behaviour, such as new bodily skills [ejaculation], demarcating spaces as private or ones that the subjects do not feel restricted from. Behaviour is identified as evidence of attempts at self agency that are linked to the body such as masturbation, which is in turn viewed as in some way sexualised simply by its nature and the way in which it may typically occur by parents and staff, whether it is or not is open to discussion.

Positioned in this way identity can be seen as a compound of numerous 'multiples' of different experiences, interpretations and actions, some vitally explicit and available to the individual and to those around them, others hidden and obscure with some features remaining incomprehensible and mysterious. This idea of multiple identities existing within one identity, can be best illustrated through using the Johari Window model designed by Luft and Ingham (1955). This model presents a simple grid to show how people may relate to themselves and to others, and identifies how certain features and the material that defines a person's identity may simultaneously be open or concealed, both to themselves and to others. See diagram below:

8:9 [fig 10: The Johari Window]

	Known to self	Not known to self
Known to others	Open: Known to self and others	Concealed: Not known to self but known to others
Not known to others	Hidden: known to self but not to others	Unknown: Not known to self or others

This model efficiently illustrates the highly interconnected and often hidden nature of the identities of the subjects in this study, and the powerful but often covert role they can play within the relationships they have with other people. This I am suggesting presents the possibility that there may be three separate identity strands within this intersection between the subjects and the people who play significant roles in their lives: First, there is the individual identity of the subject themselves; Second, the identities of the significant people around them and third, a combined and jointly accessible identity that they experience together and cultivate together, sometimes passively sometimes actively, and which has been developed over time through their combined interaction and continued contact with each other. It is located within these strands that the personal narratives of the subjects [and participants] within this study reside. Langellier(1989) suggests that the personal narrative responds to the disintegration of master narratives as people make sense of experience, claim identities, and "get a life" by telling and writing their stories. Aspects of the personal narratives of the subjects are available in these extracts, articulated and expressed through highly personalised forms of communication. Their identities and the identities of the participants are clearly inextricably linked and highly dependent on each other, and in some sense they validate each other's experience of each other. These identities are told first by the subject and then retold by others, and in this sense the meta[master]-narrative which can be defined as 'a system of interrelated and sequentially organized stories' (Stephens and Macallum 1999), becomes richer and more meaningful through the validation of the micro [personal]-narratives that drive it.

The divisive premise of identity politics, in autism as elsewhere, is that in order to legitimately represent someone else's interests one's characteristics have to reflect the other person's characteristics (Starr 2012). For the subjects within this study this was not the case, as the telling and the writing of their stories including their interests, what they want and who they are, was articulated in hugely different forms, and their individual identities within their own stories were reported on by advocates [participants] whose accounts were based wholly on shared assumptions and interpretations. In this sense the participants therefore acted in the joint role of an interlocutor and a co-constructor of the informants' [subjects] stories (Liddiard 2013). Viewed in this way it can be seen that intertwined within the construction of the identity stories of each of the subjects is the personality of the individual participants, and intertwined within the construction of the identity story of each of the participants is the personality of each of the individual subjects.

It is this experience of interconnected coexistence between subject and participant that has become identifiable within the data, a position that creates a setting within which interconnectedness can flourish and transformation for both parties can occur. Within this position radical outcomes for both parties are possible, as they naturally share and respond to each other's characteristics, from their shared central stance of being rooted in each other's stories of being and becoming. The author bell hooks (1989) writes about these theoretical marginal spaces and what they can potentially represent, stating that 'these spaces can be real and imagined, that [these] spaces can tell stories and unfold histories. These spaces can be interrupted, appropriated, and transformed. This space of radical openness is a margin - a profound edge. Locating oneself there is difficult yet necessary. It is not a safe place. One is always at risk'.

What I have presented here in this chapter is evidence of that risk. The subjects are seen to be risking to change, to step into an unknown space and create their own story, their own identity and their own experience of transformation, but it is a risk that can be enabled or thwarted by others. The notion of identity as it relates to disability is multifaceted, and there are still populations of people with disabilities who live with an identity ascribed to them that they do not want (Johnstone 2004) and perhaps would not even recognise. Within this chapter I have provided evidence of some of the different forms in which ascription of identity

has occurred both from the perspective of the participant and from the position of the subject. In this sense then, Identity can be viewed in a number of different ways;

- As a mutually accessible experience that both participant and subject can play an active role in from whatever position they adopt, with these positions always open for re-negotiated and reversal be that from a position of controller or controlled.

- A holistic experience that will lead to growth for all involved; in that the subjects will continue to present their developing mode of being and the staff and parents will present theirs, with issues around control, negotiation, misinterpretation and position very much up for grabs.

- With Identity seen as an experience within the phase defined as adolescence where the narratives of different people combine and interconnect, presenting challenges for all players as roles are established and challenged and new forms of being arrived at.

- As a phase that challenges our own understanding around who a person is, how they represent themselves, what role I as an actant play within that process and what outcomes are possible for all involved.

- As a new separate form of [self] identification that exists within the contact between all parties, that has within it; unknown qualities, unidentified outcomes and unspecified futures.

This concludes section two, the data findings section of this study, and my analysis of these four core themes of: Control, Relationships, Communication and Identity. Further exploration of the impact of the findings explored in this section, their implementation and an examination of the effectiveness of the methodological approach used within this study will be presented in section three. In this final concluding section I examine; the findings of this study; the effectiveness of the methodology I have used, what this study brings to the field of disability research, what happened next, and any indications of further areas for research and possible outcomes from the data which are discussed in full and the impact and implications explored.

Section Three: Completion

Chapter 9 Discussion

9:1 Introduction

In this chapter I present a discussion of my interpretations of the data I have analysed, explaining how the results and conclusions of this study are important and how they may influence our knowledge and understanding of the issues I have explored. I explain the implications of my findings and re-examine the original aims of this study, to consider whether these aims have been met and how the results support these aims and how this fits in with existing knowledge on the topics I have explored. I comment on the relative importance of these to my overall interpretation of the results and how they may have affected the validity of the findings. In this concluding final section I assess how effective the methodology I have designed has been in terms of gaining information from the participant's about the lifeworlds of the subjects; I examine whether the methodological approach chosen for this study has been the most efficient tool for providing access into the research process for a group of people who are often historically excluded from participation, simply because their forms of articulacy are incompatible with orthodox data collection techniques.

This research project has focused on different interpretations of behaviour, and how these interpretations might enable or disable people with autism. It has sought to understand as far as possible what the period of development termed as adolescence means for five young men on the autism spectrum, and what influence the development of an evolving sexual identity and the interpretations that others place on this, may have had on this experience. This study investigated how changes that they were going through as adolescents were impacting directly upon the social relations between those with whom they lived and worked, and this has been carried out by exploring the personal interpretations and experiences of those people involved in the lives of this group of young men. Throughout this study I have 'challenged the assumptions of the participants', in order to find out whether behaviours that appear to people positioned within the neuro-typical community to be sexualised, necessarily carry this meaning for people on the autism spectrum and how this may be determined. In this study I have sought to identify alternative modes of being that will help others to interpret more accurately the behaviour of people with autism, so that appropriate rather than

punitive support measures can be devised in relation to 'sexualised' behaviours. Essentially, I have questioned whether sexual exploration during 'adolescence' for the young men in this study group can be understood in the same way that it can for the neuro-typical majority, or whether we need to develop new ways to interpret the 'meaning' imbedded within these behaviours, which may challenge, test and trouble current understandings.

9:2 Hidden Voices

For this study I took the 'fractions' of the Lifeworld and used them as categories in which to store data during the analysis, and used the people that exist around each of the subjects to look for the 'meaning' within the things that they observed and experienced. These people were the parents of the subjects and the SNPs from the classes they were based in. These are core people, who knew the subjects well and who had histories with them, and who were eager to allow positioning of themselves within a role where they were asked to act as advocates and interpreters of that meaning. In this adapted form, those who knew the subject's well, acting within their roles as expert guides were tasked to position themselves in a role that would potentially challenge their own understanding, and shift their focus towards advocating for the student's perspective and what their communicative intention was. Lifeworld in its conventional sense is a methodology that currently excludes people who experience severe difficulty with using and understanding spoken and written language, as it relies on participants being able to report back about their personal experiences and provide 'meaning' to their actions, which is something that the students at the centre of this study were unable to do. In this study the subject's actions, behaviours and responses were all seen as communicative acts and the parents, key family members and school staff were frequently better placed than external researchers to interpret this. In this sense then the subject's were seen as jointly sharing the position of being co-participants in this study, as it is this core group who were providing the material that became available and open to interpretation and challenge.

As Atkinson (1997:9) notes, 'people with learning difficulties have very little access to the written word and, sometimes, they struggle with the spoken word too'. Through the use of this adapted form of Lifeworld, I would contest that the research process became accessible in some way to the subject's and that their voices have become articulated and are available

within the stories of the people around them. Goodley (2010) has commented on the important role non-disabled 'facilitators' can have as 'advocates' working within groups of people with learning difficulties involved in the research process. Whether this type of advocacy leads to empowerment for this traditionally disempowered group, and what types of roles are on offer for people with complex communication issues, severe learning difficulties and other forms of developmental difference – is precisely what this study has attempted to explore. This is not to suggest that people with learning difficulties cannot do research, but thus far at least, the research that has been done has been undertaken with the support of non-disabled people (Palmer and Turner 1998). What I am suggesting is that through using this adapted form of Lifeworld the students 'perspectives' and 'personal agendas' become identifiable and once identified they become powerful, assert control and can exert influence over the way in which the data are understood and responded to.

This type of participatory methodology which switches the focus through the feedback from the participants directly onto the lived experience of those unable to access standard forms of communication, is an important development for learning disability research. This can be seen as part of a progression in the history of social research into learning difficulty in general. The telling of the stories of people who are differently articulate is what teachers and health professionals are tasked to do all of the time, what I am suggesting is that in the telling of those stories, the tellers are themselves included. Positioned in this way the subjects could be described as taking on the role of participating as a passive researcher, in that they have become 'active' as both recipients of and 'contributors' to these stories through the voices of those around them. In fact one central aspect of this alternative methodological approach is the important role played by non-disabled people as participant researchers.

9:3 Epistemological position

These questions present fundamental epistemological issues that need addressing. Epistemology asks questions about 'what do we know?' and 'how do we know it?' and it works in combination with the establishing of an ontological position which is concerned with 'what is out there', both positions act as the foundations for the formation of any research questions (Vanson 2014). First, epistemological assumptions identified by Burrell and Morgan (1979) concern the very basis of knowledge, the authors ask whether it is possible to identify and

communicate the nature of knowledge as something that is capable of being transmitted in tangible forms. Second, the ontological position asks the researcher to consider the very nature of the essence of the social phenomena being investigated. And a third position concerns human nature and, in particular, the relationship between human beings and their environment. Since, from this position the human being is both its subject and object of study. From this, two images of human beings emerge – one that portrays them as responding mechanically to their environment, and one that views them as initiators of their own actions (Cohen and Manion 1994:6-7). The subject's in this study are therefore both in some sense a primary data source 'for' and active participants 'in' this study. They supply the communicative acts from which the team that presently exists around each of these students (parents, family members and staff) has extracted the meaning from.

I think it is fair to say that the subject's at the centre of this particular study were completely passive within the research process and were unaware of their own involvement. Yet the essence of their 'lived experiences' and the 'personal meaning' [for them] that may lie within their experiences, - is exactly what I am intending to uncover. Methodologically this is problematic and creates an obvious danger, one that I feel I have addressed in the design and approach of this project;

> 'If people with learning difficulties need non-disabled
> allies within the research process in order to convey
> their experiences in a way that is acceptable to the
> research community, then the question is how can
> the integrity of their accounts be maintained? And,
> how do we prevent non-disabled researchers,
> even ones who are sympathetic to the struggles of
> people with learning difficulties from assuming a
> dominant role within the research process?' (Chappell 2000:41).

One of the key things that became clear within this study whilst analysing the data was that I as the researcher was often confused about whose position I was examining, was it the parent of the young man or was it the young man himself, was it the staff member or the student [subject]. Their positions often became blurred, and I still have questions about what the data represents; Is it evidence of the Lifeworlds of the subjects I have collected in the Fractions or is it the Lifeworlds of the participants? Or, is it both? Which leads to a series of questions:

- What does this examination tell us about passive and active involvement in the research process?

- Whose lifeworlds are available within these 'fragments' - the subjects, the participants - both?

- Are the 'stories' of the participants available within the articulated responses of the subjects?

- Who 'controls' the way in which those involved are represented in the data?

- Are the experiences of the Subjects and Participant's in some way interconnected?

- Who are the subjects and who are the participants?

- Are these roles interchangeable?

- Can you be observed and the observer at the same time?

As has already been discussed, at an individual level Lifeworld research involves people telling the story of their own life, and can enable the story-teller to emerge as a person rather than as a 'case'. Ruth Finnegan (1992) goes so far as to suggest that the telling of 'personal narratives' can actually help people 'validate' their lives and make sense of their various life experiences. At present it remains an uncomfortable reality that many people with complex developmental difficulties, those who may be described as hard to reach or those who are not able to access typical forms of communication efficiently, will continue to remain very much outside of the research process, and will remain excluded from any involvement in the setting up of projects about their own experiences and their own lives. With research that may well have a direct impact on them as individuals tending to happen to them or around them rather than with them.

9:4 Interconnectivity: Shared Lifeworlds

During the data analysis phase of this study what became identifiable was a type of interconnected coexistence between participants and subjects. There were three separate 'strands' within the interrelated relationships that currently exist: the individual Lifeworld of the student subject, the individual Lifeworld of the participant and a combined and jointly accessible Lifeworld that they experience together created through their interaction with each other. Within this coexisting space there were features of both Lifeworlds; which I would

contest were both; known by the subject's [in some form] and known by the participant's and which were mutually accessible.

There were certain features of the lifeworlds of those involved in this study; motives and intentions, which were known by the subjects and known by the participants but which remained hidden or inaccessible to each other. There were things that were believed to be known about the subjects by the participants, the motives of which were obscured or unknown, features of each other's Lifeworlds which were completely inexplicable and challenging for both parties. And within this was a new entity, a third position, a shared form of intertwined coexistence that subject's and participant's were continuously involved in, feeding and developing over time, forms of relating that were vital to each actant and from within which control, power and identity formation were evolving and being negotiated.

Ruth Finnegan (1992) suggests that the telling of 'personal narratives' can actually help people 'validate' their lives and assist in making sense of their various life experiences. At an individual level, Lifeworld and the use of the fractions adapted in the way I have used them has offered people often described as 'hard to reach' the opportunity to tell the story of their own life – through the challenged understandings and interpretations of those around them, a set of stories within a set of stories containing a multitude of interconnected stories. The role of the participants [the family members and the staff] acting as 'expert guides', has been to provide their personal interpretations of what they believe the boys individual 'experiences and behaviours' mean and what they represent, for the subjects. I accept that the interpretations of the subject's behaviour given by parents and staff might differ significantly from the student's actual [in most cases unknowable] perspective and I am not suggesting that parents and staff will always be an accurate voice of the student participant's. There will always be some element of distortion during this interpretive phase, where the perception of others is misrepresented. This misreading, which has been described as parataxic distortion a term first used by Sullivan (1949) to describe the inclination to skew perceptions of others based on the fantasy of who they are, a position that Sullivan suggests we all work around. The "distortion" is a faulty perception of others, based not on actual experience with the individual, but on a projected fantasy personality attributed to the individual. However, it is likely that they [the people known to the subjects] would be a much better informed and

much more practised interpreter (Hodge and Chantler 2010), and will provide a more reliable interpretation of the communicative acts of the boys within the target group.

Positioned in this way, using this adapted form of Lifeworld has made it possible to create a participatory research experience that includes those historically excluded from the research process. It could be argued that in some sense participatory research is based on the notion of the sympathetic and committed researcher striving to improve the lives of people with learning difficulties. And that an important theme that links the methodological approaches with learning difficulty research has been the role of this non-disabled researcher who empathises with people with learning difficulties and uses his/her academic position to tell people's stories to the outside world and then argues for improved services (Chappell 1998). Within this research project using an adapted Lifeworld combined with the development of separate multi-interpretational mosaics of each student's decoded communication attempts, has led to this type of research now being undertaken in partnership with people with learning difficulties - rather than on their behalf (Chappell 2000: 41).

9:5 Summary

In closing this chapter I will return to the central aims of this study, in order to re-examine and summarise what I feel has taken place during this study and to assess whether the original aims were adhered to and addressed.

The first aim of this study was: To examine how the staff and the parents were understanding and responding to their own personal involvement in the lives of the subjects, and how that was impacting on these young men and the development of their sexual identity during the developmental phase [adolescence]. I have provided evidence to support the claim that the parents and staff participants were able to reflect on their involvement in the lives of the subjects, and that their responses have impacted both negatively and positively on the subjects. Through challenging their positions and through my analysis of the data I have located a level of interconnectivity between subjects and participants that was not seen before this study. Within this interconnection I have also provided evidence of a sense of transformation for both participants and subjects occurring during adolescence, that I believe shows the existence of a form of mutually accessible 'third' Lifeworld position.

My second aim was: To evaluate whether sexual identity formation and self exploration during adolescence, has the same meaning for people on the autism spectrum as those reported and understood by people within the neuro-typical community. In Chapters 4,5,6,7 and 8 I have provided evidence of some of the different ways in which certain aspects of the subjects Lifeworlds have been attributed with meaning by myself as the researcher, through my analysis of the data contained within the transcripts. This analysis culminated in the emergence of four separate dominant themes, these are: Relationships, Communication, Control and Identity. Within these themes 'meaning' was explicated and 'key points' were arrived at concerning some of the different ways in which the subjects are believed to have represented who they are to those around. In the extracts I have presented a series of examples taken from the transcripts which challenge conventional understandings around what sexual expression and sexual identity may signify for adolescents with autism, but which also illustrates some of the ways in which the participants have attributed meaning to what they believe the subjects were experiencing.

My third aim was: To explore whether the individual interpretations of the participants, and the meanings they attribute to the actions and behaviours they observed have an 'enabling' or 'disabling' impact on the young men at the centre of this research project. The level to which the participants both at home and at school had attempted to engage and support the students was on the whole hugely empowering. The participants were not on trial during this study, but the study did provide access to their own personal beliefs and perceptions about what sexuality represents for them. When these came into conflict with the spirit of empowerment and emancipation that this study embodied, they were commented on and included within the data, which then allowed for them to be challenged and discussed.

My fourth aim was: To develop a reliable research methodology that would provide a way of capturing the essence of the lived experiences of the young men, as it is interpreted by the parents and staff. Using an adapted form of Lifeworld in combination with the fractions in the form in which they were utilised in this study, proved to be an effective means through which to obtain access to the voices of the subjects and to garner a sense of how the participants related to the subjects and made sense of what they experienced. I would contend that the

fundamental nature of the subject's experiences, as interpreted by the participants, became

available within the data – this is discussed in more detail in the concluding chapter.

Chapter 10 Conclusions

10:1 Introduction

In this final concluding chapter I present an overall summary of what this study initially set out to achieve, I provide answers to the original questions posed at the outset of this project and I discuss methodological issues that have arisen during the research. I identify both some of the limitations of this study and recommendations for possible areas of research in the future. In this final chapter I tie together, integrate, and synthesize the issues raised in section two and discussed in chapter nine, reflecting on the aims set out in the introduction while posing possible questions to consider. This study has investigated and reported on the processes that surround the interpretation and understanding of forms of sexuality as they relate to people on the autism spectrum. My goal throughout was not only to identify these processes but also to challenge commonly held beliefs about what sexuality may represent for people with autism, and how it is typically understood for people from both the learning disabled and neuro-typical communities. In order to carry out this investigation I adopted a qualitative methodological approach with a thematic analysis, within which an adapted form of lifeworld was used. I utilised Ashworth's 'fractions' as a means to categorise the data I collected and I presented my findings as a group of four core themes with a series of sub-themes as my final data set. And finally, I summarize the principal implications of the findings, and provide recommendations for further research (Kretchmer 2017)

10:2 Research questions

The primary aim of this thesis is to explore the experiences of the research participants and through them to gain access to the lifeworlds of the research subjects, by addressing the following three questions:

First: Does sexual identity formation and self exploration during adolescence, have the same meaning for people with autism as it does for those reported by people within the neuro-typical community? Located within the data are examples of different forms of sexual expression and self-identification that challenged stereotypes of what has long been regarded as "normal", and which provided the participants with an opportunity to explore how ideas about normative notions of adolescence and adulthood can impact on young people with
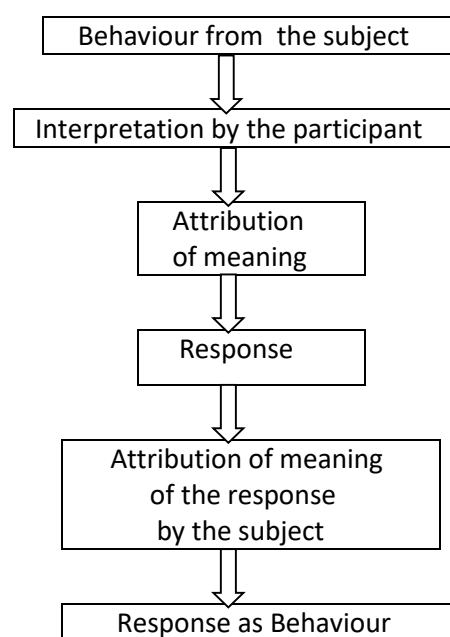
autism and their families. From the evidence available in the responses from the participants it was generally believed that sexual identity and sexual expression has developed in the subjects typically; in ways that have a clear meaning, which are to some extent understandable and which appear to have personal significance for the subjects.

For example, when analysing how the participants believed the subjects had used spaces for private touching, four of the subjects had used their bedrooms or other key spaces at home or at school for private exploration of their bodies away from others, one of the subjects [Gerry] had used both private and shared spaces. Four of the subjects masturbated privately, one subject [Mahmud] had developed the use of his room for privacy but it was not believed by his primary carer that this was used for masturbation. All subjects were described as using spaces for markedly different reasons during adolescence and a significant amount of that use of space was linked to masturbation. In terms of the way in which the subjects had developed relationships with those around them, all of the participants felt that the five subjects had changed the way in which they related with certain key people in their lives. In some situations this had meant ending long term connections, in others this had meant attempts at closeness and intimacy. Four of the subjects had objectified directly towards one person in some way, one subject [Gerry] had clearly demonstrated a preference for girls coming into his home while another subject [Arran] had developed a much deeper connection with his sister which was reciprocated appropriately and maintained. At school three of the subjects [Min, Mahmud and Chris] had chosen either staff members or other students as the focus of attention. Shifts in mood during adolescence were also reported by all of the participants for all five subjects, these changes in mood were on the whole viewed as evidence that the subjects were 're-identifying' themselves as 'different' in some way, and that the subjects were responding to changes that they were undergoing but had little understanding of. All of the participants felt that the subjects had achieved some form of sexual identity in some way whether intentionally, or simply through the changes they were undergoing, evidence of this was seen through; mood changes; getting erections; masturbating to ejaculation; touching other people; becoming aroused by others; searching out intimacy with others; objectifying other people and becoming aroused by other people. From this analysis what emerged are what O'Dell (2016) has described as "different knowledges" about different modes of being, that whilst being incomprehensively different

from the non autistic advocates, had the power to encourage new forms of understanding and new ways of interpreting for meaning. The developing sexual identities of the subjects and the different forms of sexualised expression they exhibited, presented the participants with questions around: what they themselves believed sexuality may represent, what role they played in these changes and what changes this had engendered in themselves.

Second: Do the individual interpretations of the participants within this study, and the meanings they attribute to the actions and behaviours they observe have an 'enabling' or 'disabling' impact on the young men at the centre of this research? Available in the data are a wide range of examples of both 'enabling' and 'disabling' responses, with descriptions where the participants have actively discouraged certain behaviours; where activities that the subjects have wanted to carry out have been stopped; where people the subjects have shown interest in have been removed; and where the subjects have been restricted from expressing themselves in the ways in which they have wanted to. These responses sit alongside other examples where the subjects have been sensitively supported around their need to take control over certain spaces; are encouraged to explore the forms of [sexual] expression they are engaged in; viewed as actively playing a role in their own lives and provided with a high degree of autonomy and freedom. This process of behaviour interpretation and response is illustrated in this diagram:

10:3 [fig 11: 'Behaviour interpretation and response']


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┌─────────────────────────────────┐
│   Behaviour from  the subject   │
└─────────────────────────────────┘
                 ⇓
┌─────────────────────────────────┐
│  Interpretation by the participant │
└─────────────────────────────────┘
                 ⇓
        ┌──────────────────┐
        │   Attribution    │
        │    of meaning    │
        └──────────────────┘
                 ⇓
        ┌──────────────────┐
        │     Response     │
        └──────────────────┘
                 ⇓
    ┌──────────────────────────┐
    │   Attribution of meaning │
    │      of the response     │
    │        by the subject    │
    └──────────────────────────┘
                 ⇓
    ┌──────────────────────────┐
    │   Response as Behaviour  │
    └──────────────────────────┘
```

This diagram illustrates how 'enabling' or 'disabling' interpretations of behaviour can be seen as determining the types of responses from both subjects and participants. The subjects play an equally critical role within this process but were, to a greater of lesser extent, seen as wholly reliant on the quality of responses of the participants. Enabling responses were generally seen as: ones which engendered in the subjects a high degree of control and autonomy; where the subjects communication systems were valued and encouraged to develop; Ones that lowered tension around people, spaces, events; where the subjects were provided with the opportunity to lead the outcomes and ones where the mood around the subject was relaxed, calm and where control was shared. Disabling responses tended to generate negative outcomes such as: self harming behaviours; tense moods; withdrawal from any type of negotiation around events; breakdown in communication; and less opportunities for the subjects to explore their developing identities in whatever form that may take. The level of positive [enabling] or negative [disabling] impact, was seen as being determined by the type of response to the behaviours of the subjects. However, this process of 'interpretation' and 'response' was also seen as taking place from the perspective of the subjects and the meanings they attributed to the actions and behaviours they observed from the participants, although difficult to uncover, were also viewed as having an 'enabling' or 'disabling' impact on any outcomes.

Third: Is it possible *to* construct a reliable research methodology that would provide a way of accessing and capturing the 'essence' of the lived experiences of people with different and divergent forms of articulacy?

What this methodology captured was the complex interplay between the participants and the subjects, their 'interconnectedness' and the essential nature of their co-dependence on each other. The essence of this relationship produced what can described as a third type of lifeworld which developed through their connections with each other and within which both subjects and participants were equal players - equal but different. This methodology challenged a series of positions around the way in which 'subject' and 'participant' are located within the research process by asking us to consider a number of methodological questions. Who is being observed? the subjects the participants or both? Who is doing the observing: is it the participants or is it the researcher observing the participants observing the subjects?

What is under observation and how will it be possible to extract meaningful data when these positions are so difficult to establish? This study used an adapted form of lifeworld as a theoretical framework, to gain access to the lives ['voices'] of a group of people with different forms of articulacy typically excluded from any direct influence over the research process. It used the stories of these others [the participants] to access these 'hidden' voices and what emerged was evidence of potentially multiple shared lifeworlds that all of those involved inhabited. Seen in this way then, the 'essence' of this lived experience can therefore be seen through the deep level of interdependence and connectivity that all involved in this study clearly experienced with each.

Following the completion of this study a series of issues directly related to the way in which I had approached the project became apparent and these are explored below.

10:4 Issues within the Research

Research it has been argued is a process of gathering and accumulating knowledge in order to find new meanings, discover new ideas and shed light on complex problems. Yet according to Griffith (1998:7) 'there is no hope of doing perfect research'.

> 'Research is not perfect because it is constantly evolving...
> Research is not perfect because it is error prone...
> Research is also not perfect due to its sometimes delayed...
> Value' (Glenn 2017).

Within this study there were a series of methodological issues that with hindsight I would have addressed at the outset, and these are examined below.

Data overload and Reflexivity: First, was the significant amount of transcribed data that required analysis. From my position of a lone researcher working full time as a classroom teacher in the school that the study was based in, this was often difficult to manage. The process of transcription and then thematic analysis was complex, extremely time consuming and occasionally overwhelming. It has been suggested that invariably, qualitative data analysis becomes a process of condensation in which a vast amount of data has to be condensed in a meaningful way, both theoretically and generally. And that this relates to at least three different problems: Drifting, where the results are poorly rooted in the original data. Dumping, where the results are simply not based on the data and at best present an

over simplified picture. Data drowning, where too much data has been collected and the researcher fails to get any meaningful grip on the data (LSE Online 2016). I think at times in terms of the amount of data I was confronted with I may have drowned a little. Second, it became evident to me when reading through the transcripts, that the way in which I had transcribed the recordings I had taken from the taped interviews had needed to be more managed, in order to ensure that my own biases were not observable within the transcriptions. Atkinson (1992:23) suggests rightly in my opinion that 'there is no such thing as a "natural" mechanism for the representation of speech'. I encountered this situation during my analysis of the transcripts and became acutely aware of some of the ways in which I had placed emphasis around certain phrases or what I believed were key words within the recordings. Ochs (1979:44) describes this issue stating that 'transcription is a great deal more than talk written down, in the sense that any transcription also reveals the particular stance of the transcriber – their theoretical 'home', the purposes of the transcription and their ideological position and so on: 'transcription procedure is responsive to cultural biases and itself biases readings and inferences':

> 'If doing qualitative research is about putting oneself in
> another person's shoes and seeing the world from that
> person's perspective, the most important part of
> data analysis and management is to be true to the
> participants. It is their voices that the researcher is trying
> to hear, so that they can be interpreted and reported on for
> others to read and learn from'. (Sutton and Austin 2015:1)

Reflexivity therefore is an important part of any research and is something that needs to be managed continuously within the research process (Bracher 2013:164). Coupled with an awareness that the researcher and the object of study can affect each other 'mutually' and 'continually' in the research process (Alvesson and Skoldburg, 2000) at all times. Researcher reflexivity involves thinking about how our thinking came to be, how pre-existing understanding is constantly revised in the light of new understandings, and how this in turn affects our research (Haynes 2014). Throughout this study I have attempted to keep the original voices of the participants and through them the voices of the subjects live and available, but the amount of data, the form in which it was transcribed and my position as a potentially biased transcriber were technical issues that arose.

Attendance at meetings and preparatory interview notes: From the outset of the study I had to change my research schedule around the fact that all of the parent participants did not want to attend the group meetings that I had originally planned for them. The reasons for this I believe centred around a number of factors. First was the obvious time demands that involvement in this project would entail, in that taking part in a study demands a lot of personal motivation and commitment from those willing to take part. Second were very real concerns about privacy, as within this study parents are asked to reveal potentially quite personal information about themselves, their partners, their families and their children and this can be off putting. And third, perhaps the stigmatising effect of actually participating: Parents may have felt that they or their family might be "singled out" and stigmatised as having problems if they took part (Doolan and Beckett et al 2012:8). The staff participants however, attended the majority of their group meetings, as they took place in the school and these meetings were generally arranged informally between the staff participants and myself. One outcome from this was that the notes that I had envisaged sending to each of the parents after the group meetings did not occur. These notes were expected to prepare the agenda for the one to one interviews that would follow, therefore the parents often had very minimal preparation for the conversations during the interviews. Also, my original plan to interview all parents around each separate fraction did not occur in the way in which I had expected it to, as they were not attending the group meetings where each of the fractions was first discussed, which was not the case with the staff participants was.

Male participation and involvement during recruitment: No male members of staff chose to take part and only one male [the father of one of the subjects'] from the families that were invited to take part agreed to get involved. In terms of staff take up from within the school the reasons are unclear. From the families that were invited to take part, the initial point of contact in the school had tended to be the mothers of the young men. These were mothers that I knew well and who I had known over an extended period of time. Two of the mothers were single parents with no male in the home, one of the participants was the aunt of the young man and again there was no male available in the home. The other two mothers were married but only one husband agreed to take part, the other husband declined to take part in the study in any way. Two studies; one by Scope (2012) which carried out a survey of 500

fathers entitled 'dad and me' and one by [Netbuddy], a website that provides support for people with disabilities found that; four out of ten fathers said that they do not fully understand their child's condition; seven out of ten fathers say that caring for their disabled son or daughter has severely affected their relationships with their partner; and one in three said that they are not fully confident that they know how to care for their child. Richard Hawkes the head of SCOPE commented at the time that "too often it's the mum's at the centre of the story". For this researcher the significantly low uptake of men in this study would appear to support that position, it is of interest and is difficult to account for and is worthy of further investigation.

No female students were involved in the study: The reasons why the families of female students who were invited to take part did not get involved in this study are unknown. Talking about sexuality can often be a difficult topic to discuss with parents, and it may have been the case that asking the parents of the female student's to spend a year discussing the sexuality of their daughter, and what the family does in the privacy of their home in order to negotiate that situation was a huge task for some of the parents to take on. Out of the original nineteen students who fell within the selection criteria for involvement in this study only four of those students [21%] were female, which is a relatively low cohort of female subjects to begin with considering the total amount of students available. The experience of this researcher was that studies that provide certain information about the sexual development of female individuals with autism is available (see Mehzabin and Stokes 2011; Hatton and Tector 2010; Kalyva 2010) but that this type of research tends to be large longitudinal studies that usually takes place in residential settings. No research was found on the developing sexual identities of female adolescents with learning disabilities or autism who presented with the type of profile required for involvement in this particular study.

Follow up contact: Research to date tends to suggest that for parents there is significantly more evidence of parental engagement in the early stages of primary school than there is in secondary schools (Feinstein and Symons 1999) and although this is not indicative of the overall level of parental engagement during this study, this may well be a factor to consider. There were difficulties with both sets of participants around arranging the follow up contact meetings that I had envisaged as part of the concluding end phase of the study. For parents

the length of the study meant that some of the subjects had left the school; some of the parents stepped away from the research once their direct involvement was over; or for some parents because of commitments outside of school that prevented them from taking part in follow up meetings. For the staff who had given their time to the study, the general feeling was that follow up meetings were unnecessary and that their involvement in the group meetings and one to one interviews was sufficient.

What follows are a selection of recommendations for areas of potential enquiry that were raised by this study.

10:5 Areas for Future research

From my close involvement with some of the mothers who took part in this study, it became apparent that there is a very real need for research into the ways in which schools and other care settings support lone single parents at home with adolescents with autism as they are going through puberty and beginning to explore their sexual identities. This was the initial situation that had started my thinking around what this period of adolescence can potentially mean for families [single parent families], and how I as a teacher could support a single mother who had approached me asking for help. In my experience as a SRE co-ordinator working within a special school setting, the practical application of the contents of the SRE curriculum delivered in school are extremely difficult to transfer into the homes of the students and single parents, typically single mothers tend to simply 'get on with it', often refusing support lest somebody from 'outside' finds out what that parent has had to do in order to support their son or daughter in the home. Fortunately there are now an increasing number of online support options available for lone parents such as: '@single moms and dads of special needs children', 'single parents with special needs children on 'meet up', 'Netmums', 'Gingerbread', 'Action for kids' and 'single with kids'. However, for some parents the complexity of their children's needs may often lead to them failing to engage with other parents, with schools, with online resources and with their own families and friends. This is a vastly under researched area and a tremendously sensitive topic, thick with complex ethical and moral issues which may have inadvertently acted as barriers to the type of research that it requires.

An investigation into what types of information sharing systems and ongoing practical support and advice are available for families and schools when supporting adolescents with autism, outside of the current Education Health and Care Plans [EHCP] model. Especially when transitioning into new schools, after school respite provision and overnight or short breaks provision is another area that was uncovered during this study. This may take the form of looking into what types of integrated forms of support across exist across sites, between: social care, the family home, education and respite services. These transitions are often difficult for families and other professionals to navigate and stay on top of, and transition can often be located in the stories of young people with autism and their families as areas of great challenge and failure. How person centred approaches and strategies are developed and shared with those involved in these transitions is an area of research that seems hugely under represented at the present time.

Research is required into what types of approaches are available for students who struggle to access a typical SRE Curriculum within a typical SEN school setting, ones that would provide a 'bespoke' curriculum for students and that would work across all settings; home, school and any respite or after school care that the young person used. This may also include looking into ways in which SRE advocates working across all areas of care could support and develop bespoke curriculum models that would build move with the young person. Tissot (2009) writes about some of the key barriers around the teaching of any SRE and cites: The nature of the learning difficulty; Parents' religious and cultural beliefs; The difficulties in teaching a concrete concept of privacy; The views and personal beliefs of the staff; The law; The challenges that will emerge by actually enabling sexual identity; The beliefs of society. She goes on to suggest that: schools need to get parents on board; adopt a multi-disciplinary, holistic approach; develop a curriculum 'in partnership' with all staff; audit resources across all key stages; appoint a key person to manage curriculum development and delivery; and understand that the extra SRE would only kick in if students express their sexual persona.

What I am suggesting is that any SRE topics need to be viewed simply as starting points from which to begin the exploration of what sexuality may represent for the students on an individual basis, and that this work must where possible be delivered through a student centred approach. In fact it has been argued, perhaps somewhat contentiously, that without

this type of individualized approach to education regarding the various facets of sexuality education, individuals with autism are more likely to be victims of sexual abuse (Travers & Tincani 2010:284). For students in special schools who present with the types of profiles that the subjects within this study offer, individualised programmes would appear to be the most meaningful approach to adopt, as any type of generalisation would potentially be far too complex to engage with and may lead to positive forms of contact and support rapidly deteriorating. Another critical issue within any SRE programme which is often not addressed or even attempted, is the level to which the student has some form of control or direct involvement in what is being delivered to them. Lesseliers and Van Hove (2002) have suggested that because individuals with developmental disabilities are viewed as "perpetual children," their voices in decision making about their own sexuality are often ignored. The communication and behaviour profiles of the subjects within this study challenge the typical SRE models and teaching approaches, as students who present in this way tend not to attend to taught classroom activities may not understand pictures and photographs in the way in which they are presented, and may not collaborate in the delivery of the content of a lesson in any formal way. Therefore, new and innovative alternative approaches to SRE need to be devised in order to better support students with these high levels of need. I would contend that what has become available within this study is evidence of ways in which student voice as facilitated by others can be advocated for, and that inclusion of a form of facilitated contribution from the students based on the voices of those around them has value and could be used.

An exploration of different approaches to accessing 'student voice' that are not centred around spoken or augmentative forms of language. Specifically looking into finding ways to access the voices of students who are unable to efficiently and consistently use the typical range of different forms of communication supports which are currently standard options in any special school, such as: Spoken directions and instructions, PECS, Makaton, Photographs, Objects of reference, TEEACH supports, SCERTS, PBS, talking mats, big macs, VOCA's etc. All of these forms of support have worth, and often a student will use a highly specialised global form of communication that may incorporate bits of some of them. However, there are some students placed in special schools who challenge even the most sensitive, supportive and student centred approaches, and those students are the students who have made up the

group of subjects at the centre of this study. These voices tend to exist in the telling of their stories by others, usually by group's professionals. Work around ways in which to access student voice for individuals with these types of communication profiles has been carried out by Clark and Moss (2001) who presented a simple framework for the creation of a mosaic style profile of the lived experience of young children with learning disabilities and communication difficulties. Using a range of different methods including one to one and group interviews, which can be implemented in order to combine the perspectives of a range of expert guides / interpreters in order to provide a multi-perspective picture of an event or action. This framework, imbedded in daily practise, views children as experts and agents in their own lives and focuses solely on the children's experiences and the lives they live. The strengths of this model lay in the way in which it is imbedded in daily practice and focuses on the student's lived experiences: looking at lives as they are lived rather than on any knowledge gained. And it is reflexive, in that it includes parents and staff in reflecting on meanings and addresses the question of interpretation and meaning construction. As Clark and Moss (2001:3) indicate: 'This Mosaic approach also has potential as a tool to use with older students, particularly those with communication difficulties." Specific challenges of listening to these individuals include: interpreting the student's meanings (taking into consideration the emerging concept of self, accuracy of recall, accuracy of interpretation, gender differences, power relationships, and issues of assent and informed consent (Daniel & McLeod 2005). And despite its origins within early year's childcare research, this approach may have potential for work involving young people on the autism spectrum (Beresford, Tozer, Rabiee and Sloper 2004), such as those who present with the types of communication profiles found within this study.

Finally, an exploration of the quality of training for teaching and support staff in special schools around SRE, especially around the ways in which meaning is attributed to behaviours, how different forms of sexual expression can be supported and how staff can support and train other staff in other settings. There was a wide range in the quality of approach around the ways in which the staff supported the subjects in this study, which is evidenced in the transcripts and which may well require further investigation. Through a combination of my work as an SRE co-ordinator and through carrying out of this study I have developed a training course for staff that attempts to address this situation and is currently available nationally to

all teaching and support staff throughout the UK. In my experience most staff are unclear about how to explain or clearly describe what sexuality for people with learning difficulties and autism can represent. There are often different approaches being used across schools, sometimes across classes within the same school and training around SRE has on the whole tended to remain brief, under delivered and often misunderstood.

10:6 Summary

There have been a number of outcomes from this research that have directly impacted on the work that is carried out in the school in which this study was based. First, it has presented a vision of a modified form of SRE curriculum that offers a way to revise and to reflect on a series of questions around what is both necessary and desirable to teach within SRE in a special school setting. Imry and Hinchcliffe (2014) ask the question, Within SRE Is it an inclusive entitlement for special needs [sic] pupils be taught the same as their main stream peers, or at least 'as close to the functioning of their mainstream peers as possible'. Are what is necessary and desirable the same? In other words – what are teachers required to teach. This asks any SRE co-ordinator working within a special school setting as I do, to reflect on the importance of SRE (and PSHE generally) within the curriculum as a whole. Second, to consider the role and the centrality of staff and to reflect on a core SRE curriculum that is flexible enough to teach according to individual need at any particular time. One that is capable of revisiting and thereby strengthening previous learning, and one that is also capable of building on previous learning. Third, this study has shifted my own personal and professional understanding towards a more reflective way of working and as a teacher I am now always asking staff to consider what the behaviours they are seeing represent, not for them, but for the students. This has led to staff becoming more reflective practioners and truly considering what 'meanings' and 'reasons' lay behind the behaviours they encounter on a daily basis - which has generated positive change within the school culture around the direct type of support the students receive. Fourth, I have been able to develop training for staff and parents around supporting young people with autism and SLD and have delivered this support through a training programme within the school. Finally, I have been able to develop cross-site support networks with other colleagues in order to support parents and families with some of the issues they have encountered as their sons have moved from childhood into adolescence. The change in the school culture was embodied by the leadership teams across

the primary and secondary sites, and I have worked closely with both sets of governors and senior teams to continue to develop the type of work that has grown from this study. This has led to changes in the way that we approach integrated work with other professionals, in that the expectations on therapists and other professionals working within the school is now far more geared towards them changing their professional position and adopting a far more student led approach to the work they do with the students. Adopting this alternative perspective has facilitated new work around the ways in which student voice is recognised within the school and this has led to a change in practice across sites.

New research questions that this study have generated may perhaps centre around how viewing and interpreting 'sexualised behaviour' from a more autism aware perspective could possibly lead to the development of more 'pro-active' and less 'reactive' approaches to Sex and Relationship Education, and the management of different forms of intervention around occasionally complex forms of sexualised expression. It may lead us to ask, what roles do power, control and normative interpretations of 'being' play in the support around the sexual identity of disabled / autistic people. And it may challenge us to consider what changes may be required around these forms of support if 'sexualised behaviours' are reframed as intricate 'new' indicators of changes in identity, that both the young person and those who work with them can take part in, mutually develop and learn from.

Final Thoughts: I would like to think that this study has provided a spotlight to be cast onto an often neglected area of research, namely the ways in which identities and in this case the sexual identities of young autistic men who's communication is difficult to decode, who's behaviour makes transition into adulthood a hugely complex experience for them and for the people supporting them – can be explored and celebrated. This is undoubtedly a hidden community, and residing within it are people whose stories require telling; the telling of those stories and the development of those narratives is now slowly becoming available and ready to be heard and responded to, and my belief is that the world will be a richer place by hearing them.

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Appendix 1: Recruitment and consent letter for [Parents]

Dear Parent / Carer

Hello, my name is Tom Andrews I'm a teacher at The Bridge School and I am currently carrying out a PhD research project based at Sheffield Hallam University.

A number of parents in the school have raised issues around their son's developing sexuality and I would like to know more about this situation so that we can develop our support within the school for the students, the staff and for the families and carers that we are working with.

This is a recruitment letter inviting you to take part in a study that I intend to carry out in the school, and your involvement i(f you agree to take part) will stretch over 10 - 12 months.

<u>**Research Project Title**</u>

Exploring the impact of a developing sexuality on adolescents with autism

This project has three central aims:

[1] To help teaching staff and families to interpret more accurately the behaviour of people with autism, so that more supportive measures can be devised in order to bring about 'positive sexual identity formation' during adolescence.

[2] To explore the personal interpretations and individual perspectives of some of the key people in the lives of the students at the centre of this study, in order to examine how their involvement impacts on these young people and the development of their sexual identity during this developmental phase [adolescence].

[3] To evaluate whether 'sexual identity formation' and 'self exploration' during adolescence, have the same meanings for people with autism as those reported and understood by people who are neuro-typical.

Your role in this study, if you agree to take part, will take the form of:-

- <u>8 X 1 hour Focus Group meetings</u> – Where as a group we will explore different aspects of the student participants adolescent experience. Each of the meetings will examine a specific aspect of the student's world in order to provide a clearer format for the individual 1:1 interviews that will follow the focus group meetings.

- <u>8 X 1 hour 1:1 interviews</u> - Where you will be given the opportunity to talk about your own personal experiences around the central focus area of this study. A full transcript of the interview will be made and the tape will then be destroyed, the

transcript will be numbered and coded to provide complete anonymity for the participant.

- Note: Your participation in the group meetings & 1:1 interviews is completely at your discretion, you may feel that you need only attend some of them or you may feel that you want to attend all of them – the decision is yours.

The Parents Focus group meetings would take place in the Secondary school site on the first Monday of each month [term time permitting] from 4.30 – 6.00 and a time slot of up to 90 minutes would be allotted for each meeting.

*Unfortunately, no crèche or childcare facility will be available

The 1:1 interviews would be arranged between each participant and the researcher on an individual basis.

If you have any further questions about the study, two preliminary recruitment group meetings will be arranged, one for parents and family members and one for staff [dates to be arranged] where any prospective participant who is interested in taking part in this study can come along and discuss exactly what their personal involvement in this study will entail.

If you do want to take part in the study and need more information but do not wish to attend this group recruitment meeting, complete the recruitment slip at the end of this recruitment letter to indicate that you would prefer to meet with the researcher privately and this will be arranged on a 1:1 basis.

Participation is **totally voluntary** and you are free to withdraw from the project at any point should you wish to. Your involvement would mean that you are willing to give your consent for your son to be part of this study. Your involvement would be carried out with total confidentiality, and every effort would be made to conceal the identity of all participants. No names or distinguishing characteristics will be used, and any comments or feedback recovered from the 1:1 interviews will remain confidential and anonymous.

Your sons' involvement would involve absolutely 'no change' to their standard school day.

Tom Andrews [Tel: 0207 715 0320 / Email: tom.andrews@the bridge.islington.sch.uk]

Important notes

[i] Because of the potentially delicate nature of this work, It is important that those who agree to participate in this study are made fully aware from the outset that there is an obligation on this investigator to report any disclosures of illegal practice that are reported to him by any participant during this study.

[ii] Please understand that because of the nature of the learning difficulties of the students selected to take part in this study, they may not be able to independently give their consent. Therefore your acceptance to participate will in effect mean that you have given consent for your son to participate in this work. <u>This is an important point</u> and something that you need to consider before you agree to take part in this work, please feel free to contact me to discuss this point in more detail.

Please complete the recruitment slip below and return in the envelope provided.

I agree / <u>DO NOT</u> agree to take part in this research study

I will / <u>WILL NOT</u> be attending the recruitment meeting [date to be arranged]

I will / <u>WILL NOT</u> require a 1:1 meeting to discuss my involvement in this study further

Name [please print]………………………………………   Date................................

Appendix 2: Recruitment Letter for Staff

Dear Colleague

Hello, my name is Tom Andrews I'm a teacher at The Bridge School and I am currently carrying out a PhD research project based at Sheffield Hallam University.

A number of staff in the school have raised issues around their son's developing sexuality and I would like to know more about this situation so that we can develop our support within the school for the students, the staff and for the families and carers that we are working with.

This is a recruitment letter inviting you to take part in a study that I intend to carry out in the school, and your involvement i(f you agree to take part) will stretch over 10 - 12 months.

Research Project Title

Exploring the impact of a developing sexuality on adolescents with autism

This project has three central aims:

[1] To help teaching staff and families to interpret more accurately the behaviour of people with autism, so that more supportive measures can be devised in order to bring about 'positive sexual identity formation' during adolescence.

[2] To explore the personal interpretations and individual perspectives of some of the key people in the lives of the students at the centre of this study, in order to examine how their involvement impacts on these young people and the development of their sexual identity during this developmental phase [adolescence].

[3] To evaluate whether 'sexual identity formation' and 'self exploration' during adolescence, have the same meanings for people with autism as those reported and understood by people who are neuro-typical.

Your role in this study, if you agree to take part, will take the form of:-

- 8 X 1 hour Focus Group meetings – Where as a group we will explore different aspects of the student participants adolescent experience. Each of the meetings will examine a specific aspect of the student's world in order to provide a clearer format for the individual 1:1 interviews that will follow the focus group meetings.

- 8 X 1 hour 1:1 interviews - Where you will be given the opportunity to talk about your own personal experiences around the central focus area of this study. A full transcript of the interview will be made and the tape will then be destroyed, the transcript will be numbered and coded to provide complete anonymity for the participant.

- Note: Your participation in the group meetings & 1:1 interviews is completely at your discretion, you may feel that you need only attend some of them or you may feel that you want to attend all of them – the decision is yours.

The Staff group meetings would take place in the Secondary school site on the first Tuesday of each month [term time permitting] from 3.30 – 5.00 and a time slot of up to 90 minutes would be allotted for each meeting.

*Unfortunately, no crèche or childcare facility will be available

The 1:1 interviews would be arranged between each participant and the researcher on an individual basis.

If you have any further questions about the study, two preliminary recruitment group meetings will be arranged [dates to be arranged] where any prospective participant who is interested in taking part in this study can come along and discuss exactly what their personal involvement in this study will entail.

If you do want to take part in the study and need more information but do not wish to attend this group recruitment meeting, complete the recruitment slip at the end of this recruitment letter to indicate that you would prefer to meet with the researcher privately and this will be arranged on a 1:1 basis.

Participation is **totally voluntary** and you are free to withdraw from the project at any point should you wish to. Your involvement would mean that you are willing to give your consent for your son to be part of this study. Your involvement would be carried out with total confidentiality, and every effort would be made to conceal the identity of all participants. No names or distinguishing characteristics will be used, and any comments or feedback recovered from the 1:1 interviews will remain confidential and anonymous.

Tom Andrews [Tel: 0207 715 0320 / Email: tom.andrews@the bridge.islington.sch.uk]

Important notes

[i] Because of the potentially delicate nature of this work, It is important that those who agree to participate in this study are made fully aware from the outset that there is an obligation on this investigator to report any disclosures of illegal practice that are reported to him by any participant during this study.

Please complete the recruitment slip below and return in the envelope provided.

I agree / DO NOT agree to take part in this research study

I will / <u>WILL NOT</u> be attending the recruitment meeting [date to be arranged]

I will / <u>WILL NOT</u> require a 1:1 meeting to discuss my involvement in this study further

Name [please print]…………………………………………		Date................................

Appendices 3: Selection of Research questions

Note: This is a selection of questions that were used during the interviews to initiate debate, move conversations along and to generally keep the momentum going within the interview. Often these questions would lead to other topics and when this occurred I would follow that conversation and then reposition the focus of the interview back onto the topics which was always the Fraction that the interview or meeting had been called for.

1. Sociality / Relationships

- How would you describe what a relationship is?
- What does spending time with people represent for [subject]?
- What social experiences does [subject' involve themselves in?
- When does [subject] play or interact with other peers?
- Who is a significant peer to [subject]?
- Who is a significant adult to [subject]?
- Does [subject] like to be with people or on his own?

2. Temporality

- What times of the day are difficult / easy for [subject]?
- How does [subject] use time?
- Do you have any issues around time / duration with [subject]?
- Are there any crisis times for [subject]?
- Is time something that you need to manage with [subject]?

3. Selfhood / Social Identity

- How does [subject] come across to others in your opinion?
- What makes the [subject] who he is in a broad sense?
- How does [subject] project their identity?
- What characteristics of [subject] do you feel define him?
- How would you describe [subject]?
- Describe this [subject] to me, tell me all about this person

4. Mood, tone and atmosphere

- Can you think of instances where the mood has changed around [subject] and why?
- Do you feel that [subject] can influence the mood of a situation?
- What do you think mood is in relation to [subject]?
- What does [subject] do to make a mood +/- ?
- Is there a good atmosphere between [subject] and you? If yes / no why?

5. Communication / use of language

- What is the primary form of communication that [subject] uses?
- What are the secondary forms of communication that [subject] uses?
- Does [subject] efficiently get his needs met?
- Do you have a specialised understanding of how [subject] communicates?
- How does [subject] communicate with people he doesn't know?
- What do you believe communication is?

6. Projects / activities

- What does [subject] do when alone?
- What does [subject] do when he is with others?
- What do you do with the subject that is initiated by him?
- What do you do with the subject that is initiated by you?
- What is [subject] favourite / worst thing to do?
- Tell me about what [subject] does to relax
- Tell me what [subject] does when stressed

7. Embodiment / physical & emotional feelings

- What does [subject] do when upset?
- What does subject do when happy?
- Is [subject] aware when you are upset / happy?
- Can you tell me about some of the different emotions [subject] can access?
- How does [subject] cope with distress?
- What would it look like if [subject] was in a really good / bad mood?

8. Spatiality / the spaces occupied

- Are there any specific spaces that [subject] likes to be in / go to / spend time in?
- How does [subject] utilise space, how does he use it?
- Does [subject] like to be in shared space or away from people?
- What do you think space, places, rooms mean to [subject]
- Can [subject] comfortably transition from one space to another?
- Does [subject] use spaces for specific reasons?

Appendix 4: Example of interconnections of one event across all eight fractions

Fraction	Subject	Participant	Interconnected Transaction
Space	"I don't want to leave this space / this space now represents something different to me that I am unable to efficiently communicate to others"	"I have to get you on to the school bus / I need to go to work / I am restricted from entering this space now"	The form in which negotiation around the way in which the bedroom space is used proceeds
Time	"I may require an indefinite amount of time in this space now / having a time limit placed on how long I spend in this space may be distressing for me"	"I have a limited amount of time that I can spend on negotiating this space / I am receptive to the need you now have for this space"	Duration of time for subject and participant may become an area of conflict and distress
Communication	"I may communicate how I wish to use this space in ways that may be difficult for others to understand / I may not be aware that I am required to communicate about this	"our forms of communication about this space may lead to tension for both of us / we may both learn about each other's communication from this"	The opportunities for both subject and participant to gain knowledge about the way in which communication can develop is available
Mood	"I may create a change in the feeling tone or atmosphere between us in order to communicate exactly what this room now represents for me / this room now makes me feel like this"	"I get tense when you refuse to leave your room / I understand that your room is now vital and I will try to alleviate that stress for you"	Subject and Participant both 'experience' something and the dynamic feeling-tone is seen an essential element of this situation
Identity	"My use of this room is now one of the ways in which I define who I am becoming"	"I can see that this room has taken on a new meaning"	The subject is validating who they are through the way this space is now negotiated

Project	"this space now represents an area where I can explore who I am becoming and who is important to me / this is a space that I can be private in [away from the scrutiny of others]	"What is happening in there that I am unaware of / what does it feel like for me to now be excluded from the 'becoming' of the subject	You are involved in my becoming / you are excluded from my becoming – this may occur from both subject and participant simultaneously
Sociality	"I am restricting access to you / I am allowing you in / I am choosing"	"I am allowed in / I am not allowed in"	How the use of this space affects or depends on relations with others
Embodiment	"What do I do physically in this space with my body that represents what it may signify for me now"	"How do I manage the different ways in which you now physically use your body in that space, both emotionally and practically"	"I am struggling with your new physicality / I am learning how to sensitively negotiate your need for a new way in which to physically represent who you are"

Appendices 4: Confirmation of Ethical Approval

Our Ref   AM/SW/1a-2010

Sheffield Hallam University

SHARPENS YOUR THINKING

Tom Andrews

PhD Student

Faculty Development & Society

Arundel Building City Campus

Dear Tom

Request for Ethical Approval of Research Project

Your research project entitled "Exploring the impact of sexuality on the Lifeworld of 'adolescents' with autism " has been submitted for ethical review to the Faculty's rapporteurs and I am pleased to confirm that they have approved your project.

I wish you every success with your research project.

Yours sincerely

Professor A Macaskill

Chair

Faculty Research Ethics Committee

Faculty of Development and Society

Application for Research Ethics Approval

Staff and Postgraduate Research Students

Section A

Important Note- If a previously submitted research proposal answers the methodology questions in this section, please include a copy of the proposal and leave those questions blank. You <u>MUST</u> however complete ALL of Section B

1. **Name of principal investigator:** Thomas Andrews

   Faculty: Development and Society

   Email address: thomas_andrews_72@hotmail.com

2. **Title of research:**

   Exploring the impact of a developing sexuality on adolescents with autism

3. **Supervisor if applicable:**

   Email address: Dr Nick Hodge [n.s.hodge@shu.ac.uk]

                Dr Luke Beardon [l.beardon@shu.ac.uk]

                Dr Karen Dunn [Karen.dunn@shu.ac.uk]

4. **ENT number if applicable:** N/A

5. **Other investigators (within or outside SHU):** N / A

Title	Name	Post	Division	Organisation

6. **Proposed Duration of Project:**

Start date: Jan / 2010   (after ethics approval secured)
End Date: Dec / 2014

7.   Main purpose of Research:

X☐   Educational qualification

☐   Publicly funded research

☐   Staff research project

☐   Other (Please supply details)

Acknowledgment

I would like to thank the panel for their honest feedback on my Ethics form, their comments were valid and have really helped to refine and redefine my approach to the study I am intending to embark on. This process of re-examination has helped to strengthen my proposal and has provided me with a much clearer understanding of what I am trying to achieve, I have taken on board all of their observations and have addressed them in this combined response.

8.   Background to the Study and Scientific Rationale (500 words)

The primary reasons for wanting to pursue this research project evolved over one academic school year [2007-2008], while acting as the PSHE co-ordinator for the school I am presently working in. I was approached by some parents who had concerns with what they referred to as 'highly sexualised' behaviours being demonstrated by their sons who are on the autism spectrum, these parents had no experience of this situation and wanted to know what the school could do to support them. This study will attempt to explore this process of sexual identity formation during adolescence for a small group of male students on the autism spectrum and will provide a space to reflect on how parents/carers and school staff interpret the behaviour of teenagers with complex communication and social issues and identify the impact that these understandings may have on the Lifeworlds of these young people. My experience of working with these students is that they currently have no voice in relation to how their sexual identity is being perceived and understood by others. Therefore through using the literature accounts of writers on the autism spectrum this study will reflect with parents and staff on different interpretations that might be made of behaviour and evaluate the impact of these different understandings on the lifeworlds of the adolescents concerned.

This study will also evaluate whether through the process of discussion and exploration with those who know the young people well it is possible to enable access to the lifeworlds of young people with complex social and communication issues; thereby including them within a methodology that currently appears to exclude them.

The central aims of this study are:

- To explore the personal interpretations and individual perspectives of some of the key people in the lives of the subjects at the centre of this study, in order to examine how their involvement impacts on these young people and the development of their sexual identity during this developmental phase [adolescence].

- To help teaching staff and families to interpret more accurately the behaviour of people with autism, so that more 'appropriate' support measures can be devised in order to bring about 'positive Sexual identity formation' during adolescence.

- To evaluate whether sexual identity formation and self exploration during adolescence, have the same meaning for people with autism as those reported and understood by people who are neuro-typical.

- To design a methodology that would provide clear qualitative evidence of the effects of these 'interpretations' and 'personal perspectives', and one which would provide an insight into the impact of the role played by the people around them, allowing an opportunity for their positions to be sensitively examined and its impact explored.

Following completion of this study I hope to be able to provide a 'tool kit' for parents designed to support families with young adults with autism, who are experiencing difficulties related directly to sexual identity formation and complex sexualised behaviour. Combined with a school support programme for staff working with these students, which would raise the profile of positive sexual identity formation and provide new strategies for support.

9.   Has the scientific / scholarly basis of this research been approved? (For example by Research Degrees Subcommittee or an external funding body.)

X☐   Yes

☐   No - to be submitted

☐   Currently undergoing an approval process

☐   Irrelevant (e.g. there is no relevant committee governing this work)

10.   Main Research Questions

1. Does sexual identity formation and self exploration during adolescence, have the same meaning for people with autism as it does for those reported by people within the neuro-typical community?

2. Do the individual interpretations of the participants within this study, and the meanings they attribute to the actions and behaviours they observe have an 'enabling' or 'disabling' impact on the young men at the centre of this research?

3. Is it possible to construct a reliable research methodology that would provide a way of accessing and capturing the 'essence' of the lived experiences of people with different and divergent forms of articulacy?

11.   Summary of Methods including Proposed Data Analyses

It is expected that data collection within this project is likely to take between eight to ten months and will take place in a series of stages following recruitment of the participants. There are three separate data collection phases within this study with the central Lifeworld methodology acting as the primary source of data collection throughout.

Recruitment

The process of recruitment of the participants for this study will be carried out in three ways:

[1] **By letter**: All parents whose sons fall within the selection criteria for this study will be provided with a recruitment letter which they can complete and return. In this letter it will be made clear that through accepting to take part in this study they are consenting to their sons' involvement in the study. All other family members, school staff [teachers, teaching

assistants] and non school staff [therapists, key workers], will be also be invited to take part in this project by recruitment letter. [see appendix (i) Recruitment & consent letter]. The recruitment letter may also offer some potential participants who may wish to take part, the opportunity to agree to involvement in the study whilst remaining completely anonymous. For these participants any further involvement they have in the research process may take the form of individual 1:1 meetings negotiated with the researcher. In this way a participant would be able to take part in the entire study without their identity or involvement being revealed.

[2] **Through attending an 'Introduction and Recruitment meeting:** All potential participants will be invited to attend an 'Introduction and Recruitment meeting' where they will be given detailed information about their involvement and the aims and objectives of the project, at this meeting they can choose to either accept or decline to take part in the project. Attendance is completely voluntary and some participants may simply agree to participate by returning the acceptance slip on the initial recruitment letter without attending this meeting. This initial meeting is primarily concerned with recruitment and participation in this study, for those attending it will be made clear at the outset that involvement is completely voluntary and that this meeting is being provided for those participants who: may wish to hear in greater detail what exactly this study is all about, who may wish to meet up with other people who are taking part in the project, for those who may need the support of other parents who have agreed to take part, or to alleviate any initial fears they may have about what 'an interview with the researcher' may entail. Before any attendance all participants will be cautioned about the potential pitfalls in divulging or discussing any delicate or sensitive information in a group situation, and the importance of confidentiality when sharing personal information in group meetings. These initial meetings are strictly for recruitment purposes only, and there will be no data gathering of any kind.

NB: School staff and other staff who have been invited to take part in this project will be provided with a separate recruitment meeting which no parents / family members will attend.

[3] **1:1 Meetings**: Parents / family members and staff who may feel uncomfortable about attending a large group meeting, but who may need more clarification about exactly what their involvement would entail but who may wish to keep their involvement confidential,

would be offered the option of having a private 1:1 meeting where they could either accept or decline to take part in the project.

<u>A note on the option to withdraw from the study</u>

Within this 'introductory letter' and at the 'introduction & recruitment meeting' it would be made explicitly clear from the outset that all potential participants have the right to withdraw from this study at any point if they wish to do so, and that all attempts will be made to remove any data related to their involvement from the study.

NB: Data will only be gathered once participants have consented to be a part of the study and this initial stage of the project **does not** form part of the data collection process.

Data Collection

The methodology that I intend to use within this study is Lifeworld, which uses the shared accounts of people to assist with the complex task of interpreting the behaviour of others, this can be achieved by assessing exactly how ways of being are interpreted and perceived by different people in different ways. This will be used in conjunction with a thematic analysis of the using Ashworth's (2003) fractions of the Lifeworld as a way in which to categorise the data.

The questions I intend to use throughout this study will always focus wholly on the 'personal experience' of the parents, family members and staff and their interpretations and individual perspectives on the ways in which the students at the centre of this study experience 'key features' of their world. Throughout this study the principle focus is on the staff, family members and parents acting as 'interpreters' or 'expert guides' and using the student participants communication attempts to provide a way to interpret the meaning that these experiences have for the boys in the target group. For this study I intend to use an adapted form of this methodology which currently excludes people with complex communication difficulties that will explore using the team around the student (parents, family members and staff) to act as interpreters of that meaning.

The methodological approach chosen as the principle data collection tool for this study will combine three forms of data collection:- [1] group meetings, [2] '1:1' interviews and [3] research notes taken in the meetings.

[1] Group Meetings [Data collection method 1]

There are a number of key reasons for using a series of 'group meetings' as one of the key forms of data collection for this study, aside from the role they would play in revealing the nature and range of the participants views, generating issues and assisting in the development of a clear starting point for the each of the 1:1 interviews that would follow each meeting. Robinson (1999) suggests that one of the advantages of using a focused group meeting is that participants tend to enjoy the experience and that they can find the process empowering, participants are able to make comments in their own words, while at the same time being inspired and motivated by the thoughts and comments of the others in the group. This is especially successful when discussing difficult issues around sexualised behaviours and taboo subjects [e.g. masturbation and inappropriate touching in public], when less inhibited members of the group have broken the ice and have ended up providing mutual support for those parents who were unable to explore such topics. This method also helps to encourage contributions from participants who may initially feel quite reluctant about speaking out about their experiences, as they see how valued the contributions of the other members of the group are. Focus groups can therefore serve a number of different purposes;

[i] They are a highly efficient technique for qualitative data collection since the amount and range of the data are increased by collecting from several participants at the same time.

[ii] Through using group meetings in this way contributions can be encouraged from participants who may initially feel reluctant about being interviewed on their own, or who feel they have nothing to say or who may not usually take part in a survey.

[iii]Group dynamics can assist in focussing on the most important topics and it is fairly easy to assess the extent to which there are contrasting or shared views within the group.

[iv]They provide self-contained data specific to the specific areas under investigation.

[v]Facilitation can help in the discussion of taboo subjects and sensitive issues.

[vi]Participants also tend to enjoy the experience.

(Adapted and abridged from Robinson, 1999, pp. 909-10.)

The group meetings and interviews will use what Peter Ashworth (2003) argued were the 'key aspects' of being alive which were shared by us all, they are he argues, the parts of the Lifeworld which were not bounded within themselves but which were experienced fluidly with each aspect influencing and being influenced by the other. These key aspects are described within the Lifeworld methodology as 'fractions' and they act as a way of scaffolding the data and creating a context for the responses from the participants.

Within this study these fractions are; [1] selfhood (social identity);[2] Sociality (relationships with others); [3] Embodiment (physical & emotional feelings); [4] Temporality (sense of time); [5] Spatiality (the spaces occupied); [6] Projects (activities); [7] Discourse (use of language) and [8] 'Mood as atmosphere' or the 'feeling tone' of any situation. Ashworth termed these aspects 'fractions', to emphasise that they were not separate dimensions but that they were interconnected parts of a whole. Each of these 'fractions' will be explored individually in terms of how they impact on the development of the sexual identity of the students at the centre of this project. There will be eight focus group meetings with each meeting taking one of the eight 'fractions' mentioned above as its central focus.

- Meeting 1: Social Identity

- Meeting 2: Relationships with others

- Meeting 3: Physical /Emotional feelings

- Meeting 4: Examining the student participant's sense of time

- Meeting 5: How the students cope when occupying different spaces

- Meeting 6: Activities that the students are actively involved in

- Meeting 7: Individual non-verbal communication systems

- Meeting 8: **'**Feeling tone' how the students experience the 'mood' of any given situation

Each of the meetings will examine specific features of each of these fractions in order to provide a clearer format for each separate session. This format will then provide a more precise individual focus for each of the 1:1 interviews that will follow the focus group meetings. These meetings will take place in the school on the first two Mondays of each month [term time permitting] and a time slot of up to 90 minutes would be allotted for each meeting.

- [First Monday] Meeting for parents & family participants 6.00 – 7.30

- [Second Monday] Meeting for staff and non-school staff participants 3.30 – 5.00

The group meetings for staff and the meetings for parents and family members will be held separately and will be managed by myself. Each meeting would be structured around each of the 'fractions' under examination and I intend to prepare an introduction script explaining the purpose of each meeting and how each of the groups will run. All of these group meetings will be tape recorded, feedback and responses from participants attending will be recorded on flip charts by the researcher during the meetings.

Note:

All participants who attend the group meetings will also be provided with an evaluation sheet with which they can comment on the running of the study and the way in which the primary researcher is managing the project. This is one way in which to monitor any conflicts of interest that may inadvertently develop, to ensure that the primary researcher is remaining objective and to make certain that all participants are comfortable with the way in which the study is being managed. [Please see appendix (ii) evaluation form attached]

1:1 Interviews [Data collection method 2]

Combined with the focus group meetings, each participant will take part in a series of eight 1:1 interviews throughout the duration of the study. Each of the interviews will examine aspects of each of these fractions in order to provide a clear format for each of the interview sessions. In these interviews the researcher is searching for statements that capture the essence of the experience for the participant, what they believe the students' behaviour

represents and critically to identify the meanings that they feel the student participants make from their experiences. Each participant would be asked to decide what they wanted their interview to focus on following the focus group meeting, and this would be agreed with the primary researcher at the beginning of the interview. In this way each interviewee is able to set their own agenda following the more structured format of the group sessions. Used in this way face to face interviews offer the possibility of modifying and adjusting the line of enquiry, following up interesting responses and investigating underlying motives in a way that may not be possible in the focus group meetings (Robson 2002).

These individual 1:1 interviews would take place following each of the focus group meetings, and would provide the participants with the opportunity to explore confidentially and in much greater depth, their personal experiences of different aspects of the 'fraction' examined in the group meeting. The questions in the interviews will focus exclusively on the personal experiences of the interviewee and will be designed to allow the participants beliefs, views and feelings to emerge. The aim of these 1:1 interviews is to focus on the interpretation and meaning attributed by the participant 'expert guide' around a specific 'fraction', from the communicative attempts provided by the student participant. The emphasis here is not on the experience of the parents but on their interpretation of the experience of the boys and this applies to all other participants [family members and staff] who are ultimately carrying out the role of interpreting what they see. The exact design for the questions for each interview is not yet formulated, however a range of possible questions and possible areas of focus which may be examined are provided below;

- How do you think your personal understanding of the 'sexualised' behaviour you have witnessed impacts on the subjects.

- What do you think these sexualised behaviours represent for the subjects at the centre of this study.

- How do you think others react to these behaviours? and how is that experienced by the subject.

- What do you think these behaviours mean to the subject?

All interviews will be tape recorded and transcribed; following transcription the tapes will be destroyed. All participants' names will be given a letter, e.g; Parent A / Staff B and all students will be referred to with a pseudonym.

NB: All participants will be provided with a timetable of the group meetings listing, time, date, duration of the meeting and monthly focus and individual interviews will be planned for each participant following these meetings.

Research Notes: [Data collection method 3]

I will make notes during the group meetings of any significant comments presented by the participants.

<u>Completing the study</u>

To draw the study to a close once all of the participants [staff and families] have completed their involvement in the project, they will all be individually offered the opportunity to report back on their involvement in the process. This 'follow up' procedure will be in the form of either:-

[1] <u>A group meeting:</u> All participants will be invited to a 'Concluding group meeting' where they will be given the opportunity to talk about how they may have been affected by taking part, what they have taken personally from their own personal involvement, and what impact they believe the project may have had on the way in which they view the experiences of the boys in the target group.

N.B: Separate meetings will be arranged for staff and parents and families to ensure that confidentiality and anonymity are retained right up until final completion of the study is carried out.

[2]<u>Individual 1:1 meetings:</u> For those participants that would prefer to carry this completion process out privately where they can discuss their involvement in this project in confidence, 1:1 meetings will be offered to them on an individual basis as required.

<u>Regarding feeding back to students</u>

Within this work I refer to the students in this study as participants because this study is for them and all about them, but actually they will not be aware in any sense that they are the focus of this research. Feedback on the research process will therefore be given to parents and staff but not to the students.

NB: The feedback from this final group meeting and from the individual 1:1 meetings will be recorded and included as part of the data collected at the culmination of the study. The 1:1 interviews will be taped but not transcribed verbatim, the group meetings will be taped and flip charts will be used to record comments and feedback from those present.

This final concluding stage completes all of the data collection procedures for this study.

Follow up support workshops

Following these final meetings, all staff and non-staff participants will be offered a series of workshops run very much along the lines of the current 'parent/school support groups'. These workshops will attempt to explore the issues examined in the focus groups and will provide all participants with an opportunity to look at the current strategies being used and the personal experiences that would have emerged from the study, in order find ways in which to better support the students in terms of creating positive sexual identity formation both in school and at home. The emphasis of these workshops will be on providing practical assistance and long term support for parents, families and staff and on how to develop positive strategies to assist and support the students.

The precise content of these post study workshops would it is hoped emerge from the data collected.

NB: The feedback from these support groups does not form part of the data collection process for this study.

*[I identify clearly what procedures I intend to put into place if there is any disclosures of 'unsafe' or 'what may be considered harmful' practises later in this document, please see: [*Section* B. 3].

Section B

1.   Describe the arrangements for selecting/sampling and briefing potential participants. (This should include copies of any advertisements for volunteers or letters to individuals/organisations inviting participation.)

[*Please see 'Recruitment & consent Consent letter' attached]

From the 75 students who attend the school only 19 students fit the profile I have designed and those students throughout key stage 3, key stage 4 and the 6th form. From the informal feedback I have received so far from parents I have spoken with, I am confident that I will be able to choose between 5 students [the proposed number of student participants I intend to use in this project] from this group, but at present it is unknown which students will actually form the target population of this study, and any one of them may come from within this age range, from anywhere within the school population.

What is important is that the student participants fall within an age range that may generally be held to represent 'adolescence'. The developmental level of the students is more difficult to determine and in some ways is less important, all that is required is that these students fit the requirements of the study which are : -

- A student who has a clinical diagnosis of autism.
- A student who does not access typical forms of communication efficiently, typically positioned below or at P3 to P4
- A student who fell between the age range of 12 to 16.
- A student who had been described by staff or parents as exhibiting what they described as 'sexualised behaviour'.
- A student who had been described by staff or parents as exhibiting what they described as 'sexualised behaviour'.

The decision to choose 5 students was based on the number of interviews with family members and staff that this number of students could potentially generate. Using less than 3 students would in the opinion of this researcher provide an inadequate amount of data for this study, whereas using more than 5 students would create too much work for this researcher to cope with in the time frame that this study is expected to be carried out in.

2. What is the potential for participants or third parties to benefit from the research?

The potential benefits from this study would span a wide range of different areas, for example, it may provide:

[i] A more supportive approach towards certain key issues related to Sex and Relationships education within the school, especially around; what constitutes a sexual expression and the ways in which we may support the students in their attempts at self exploration and positive sexual identity formation.

[ii] A more experienced and knowledgeable staff.

[iii] It may establish a more student based approach with the student's 'learning style', 'personal sexual orientation' and 'individual personality type' becoming the centre of any projected work around the development of their sexual identity.

[iv] There is the potential for a complete re-evaluation of current practice around the management of 'sexualised behaviours' in the school and at 'home'.

[v] It may act as a way of highlighting the issues that some parents have raised around the difficulties that they are experiencing at home, in order to invoke change through offering support and through sharing their experiences with other parents and with staff working with these young people.

[vi] How, by attempting to Interpret 'sexualised' behaviour' from the perspective of a young person on the autistic spectrum we may be able to:

    [a] Develop more 'pro-active' and less 'reactive' approaches to Sex and

        Relationship Education.

    [b] Develop different forms of intervention around complex sexualised

        behaviours.

[vii] It may offer us an opportunity to explore how 'control' is exerted over

people with autism.

[viii] It would help to support the concept of 'positive sexual identity formation' as an ongoing process, that all of the people involved in the lives of the students could take part in and contribute to.

3.Describe any possible negative consequences of participation in the research along with the ways in which these consequences will be limited.

Procedure if a parent describes what I regard as illegal practice?

I am acutely aware that the students who form the group at the centre of this study present behaviours that may outwardly appear odd or bizarre and that often when working with them these behaviours simply become typical and in a sense quite normal. Nudity and what could be described as 'inappropriate touching' are common place and for some students deeply entrenched acts that may form part of their daily routines, ways of 'being' and forms of self expression. It would be extremely easy to view many of these types of behaviours as 'illegal', when viewing them out of the context of the students learning style and without taking into account the extremely complex nature of their communication needs and their highly individualistic ways of accessing sensory stimulation. Therefore I would see it very much as part of my role as the primary researcher within this study to act as a filter, as to exactly what behaviours I would regard as 'illegal or abusive practise'.

The types of disclosures that I would consider worthy of action would involve any type of **Physical Abuse** which could be described as the infliction of physical injury as a result of punching, beating, kicking, biting, burning, shaking or otherwise harming the student. Even if the parent, family member or staff member may not have intended to hurt the student. Any form of **Neglect** which for this researcher could be characterized by the failure to provide for the child's basic needs, this may involve physical, or emotional deprivation, it may include refusal or delay in seeking appropriate health care or inadequate supervision. Any form of Emotional neglect which may include such actions as marked inattention to the child's needs for affection; refusal or failure to provide needed psychological care or spouse abuse in the student's presence. And of course any type of **Sexual Abuse** including disclosures that related directly to the fondling the student's genitals, intercourse, incest, rape, or sodomy.

For this researcher any action that needed to be taken relating to the disclosure of any reported behaviour that may be construed as 'illegal practise' or 'abusive', would become an

issue for the designated child protection officers currently working in the school. And, if any disclosures were made I would adhere to the schools child protection guidelines that are currently in use, these are;

[i] If the primary researcher received a disclosure of abuse or suspected that abuse may have occurred it would be reported as soon as possible to one of the Deputy Head Teachers, who are the designated teachers for child protection issues. The matter would then be brought to the attention of the designated person in charge of the site in the absence of the Deputy Head Teacher.

[ii] If the primary researcher noticed signs or symptoms of possible abuse in a child or young person, he would make notes as soon as possible (e.g. within an hour), writing down as exactly as possible, what was seen and putting the scene into context, time and location. Dates and times of events would be recorded as accurately as possible, together with a note of when the record was made.

[iii] The designated teacher would then co-ordinate any action on child abuse within school, ensuring that all both the primary researcher and any staff/non-staff are aware of their own responsibilities in relation to child protection.

[iv] The designated teacher who is responsible for child protection within the school would then be responsible for referring individual cases of suspected abuse to the Social Services Department, and for liaising with the Social Services Department and other agencies on these and other general issues relating to child protection.

Any further action would become an issue for myself, the school that this research project is based in and my supervisory team, and I would be advised by both the school and my supervisory team as to how to manage this type of situation, if it did occur during this study.

Measures in place to reduce risk to both participant and parent around emotional stress?

Any **student participants** taking part in this study will not be placed under any undue stress, and any involvement from them would be carried out simply as part of the daily routine of

the class. For this group of participants any involvement would entail **NO** change to their standard day to day home / school experience.

Any **parent, family member or staff member** taking part in this project would be provided with complete support by myself throughout the duration of this study. The precise nature of this support would depend very much on the nature of the issues that may arise, but it would essentially take the form of 1:1 advice and support as and when it occurred, depending entirely on the level of risk / stress experienced by each participant through their involvement as the study progressed. The option available to all participants at the very outset of the study, of carrying out their involvement without attending the group meetings or final completion and support group meetings, may also act as one way to reduce emotional stress for some of the participants. I would take advice from my supervisors on any issues that I believed were more serious or required more action.

How do I ensure that parents do not end up feeling that their children are being seen as 'research guinea pigs'?

I would stress at the beginning of the study with all parents who have agreed to participate, that any involvement from the students would be embedded in the daily routine of their class group and their typical daily home life and that at no time would their son be taken out of their typical work routine that they are accustomed to. I would stress that the purpose of this study throughout its duration is to provide support and improve the educational experience for these 5 boys and in no way hinder it.

4. Describe the arrangements for obtaining participants' consent. (This should include copies of the information that they will receive & written consent forms where appropriate). If children or vulnerable people are to be participants in the study details of the arrangements for obtaining consent from those acting in *loco parentis* or as advocates should be provided.)

[Please see Recruitment & Consent letter attached]

This central aim of this project is to explore the worlds these students inhabit primarily through the interpretations, perceptions and personal accounts of the people involved with their care and support. Therefore it could be argued that in one respect the scale of the

students involvement is 'total' as every facet of their Lifeworld is potentially under scrutiny, as key zones of their experience (the 'fractions') are to be examined and explored in some detail.

However, the actual involvement of the students participating in this study will not take any different form other than that which is observable within their 'standard day' within the school, and at home outside of the school. The students are therefore passive participants throughout the entire study, as their involvement will be that of 'research subject' for the participants to talk about. However, their role is critical through simply providing the observable 'interaction and behaviour', that will determine the feedback and responses from the people who inhabit their Lifeworld, and who have agreed to take part in the study. I am aware that this presents considerable ethical issues around the way in which people who cannot give consent are included in research of this type and I intend to explore this as part of the concluding section of the study.

Therefore from the outset all parents would be informed that through their participation they are allowing consent to be given on behalf of their son, who for the duration of this study would not able to give informed consent independently. There are no students presently attending the school who live outside of the family home, therefore the issue of providing a non-biological parent with the legal rights and responsibilities of a biological parent are not an issue in the case of this particular study.

5. Describe how participants will be made aware of their right to withdraw from the research. (This should also include information about participants' right to withhold information.)

It would be made explicitly clear from the outset of this study, primarily through the initial recruitment letter that would be sent out to any prospective participant and then at the introduction and recruitment meeting that all potential participants have the right to withdraw from this study at any time. Projects should always attempt to be as transparent as possible in their planning, and it is clear for this researcher that in most cases, the ethical duty to the participant and the risk to a project for loss of goodwill are more than sufficient to offset any possible gain by retaining the data, and this project would always accede to the participant's request in the final instance.

It may be true that for some qualitative studies the withdrawal of existing data can be very damaging to a study with a small number of participants. For this study, the researcher does not want to be in a position of retaining data if a participant wants complete and total withdrawal. Therefore all staff and family members who wish to participate would be informed at the outset that their involvement is held in high regard and that if they feel uncomfortable at any time and wish to remove themselves from the study they can do so at any point. And, because of the severe nature of the learning difficulties and the complex communication difficulties of the students at the heart of this study, any consent that had been granted through the involvement of their legal guardian's would also be withdrawn – and their involvement would cease immediately.

However it is important to also bear in mind that these issues of 'personal involvement' and 'giving consent' are part of an ongoing evolutionary process that may alter as the study expands and changes. Therefore for this study it will be beneficial to all involved if the right to withdraw is made explicit <u>throughout</u> the participants involvement and incorporated into the study as it evolves.

6. If your data collection requires that you work alone with children or other vulnerable participants have you undergone Criminal Records Bureau screening? Please supply details.

 YES, I have a full up to date CRB check as of August 2017. I would not be engaging in any practice with a young person that would not be part of my usual teaching activity.

7.Describe the arrangements for debriefing the participants. (This should include copies of information that participants will receive where appropriate.)

To draw the study to a close once all of the participants [staff and families] have completed their involvement in the project, they will all be individually offered the opportunity to report back on their involvement in the study. This 'debriefing' procedure will be in the form of either; a group meeting or a private 1:1 meeting with the primary researcher. At these meetings all participants will be invited to talk about how they may have been affected by taking part, what they have taken personally from their own personal involvement and what

impact they believe the project may have had on the way in which they view the experiences of the boys in the target group.

The feedback from these final group/1:1 'debriefing' meetings will be recorded and included as part of the data collected at the culmination of the study. The 1:1 interviews and the group meetings will be taped but not transcribed verbatim, the group meetings will use flip charts to record comments and feedback from those present. Separate meetings will be arranged for staff and parents and families to ensure confidentiality. This final concluding stage completes all of the data collection procedures for this study.

Follow up support workshops

Following these final meetings, all staff and non-staff participants will be offered a series of workshops run very much along the lines of the current 'parent/school support groups'. These workshops will attempt to explore the issues examined in the focus groups and will provide all participants with an opportunity to look at the current strategies being used and the personal experiences that would have emerged from the study, in order find ways in which to better support the students in terms of creating positive sexual identity formation both in school and at home. The emphasis of these workshops will be on providing practical assistance and long term support for parents, families and staff and on how to develop positive strategies to assist and support the students. The precise content of these post study workshops would it is hoped emerge from the data collected.

Note: The feedback from these support groups does not form part of the data collection process for this study.

8. Describe the arrangements for ensuring participant confidentiality. (This should include details of how data will be stored to ensure compliance with data protection legislation and how results will be presented.)

All of the research will conform with legislation relating to data protection and any details that would allow individuals to be identified will not be published, or made available, to anybody not involved in the research unless explicit consent is given by the individuals concerned to do so. The resulting data from the 'group meetings' [data collection method 1] and the 'Concluding Group meetings' will recorded on flip charts by the researcher during the

meetings. All written data collected and any correspondence will be stored safely and securely in the school in a locked cabinet in the administrative offices of the school at all times and all electronic data/e-mail correspondence will be stored in a secure file which will only be accessible to the primary researcher. Interview transcripts will be coded and the names of any participant will be altered to ensure that their identity is protected.

Because of the nature of the group meetings the identities of all of the attendees will obviously be known to the participants present. Therefore it will be made clear from the outset that any participant who wishes to divulge 'confidential' information may wish to do so in their private '1:1 interview' [data collection method 2], that would follow each of the group meetings. The feedback from these 1:1 interviews will be transcribed and the participants' identities coded and included in the appendices.

Given that there are multiple informants for each student, it is essential that information and personal details about each of the participants will not be available or shared across informants (i.e. that information from staff will not be available to parents). To ensure that this situation does not transpire a number of safety measures will be put in place, these are:

[1] The parents/families meetings and the staff meetings will be held a week apart, with the parents/families meeting held after 6.00 p.m when all of the school staff have left the building.

[2] All participants will be briefed at the outset of the study about not discussing the content of the meetings they attend, or the identities of the people attending the meetings. This issue of 'personal responsibility towards the other participants within the study' will be raised throughout the duration of the project with both groups, to ensure that this issue of confidentiality and participant anonymity is being adhered to as far as possible.

[3] All data and information will remain stored safely and securely to ensure that no information is available to anyone participant or otherwise at any time.

9. Are there any conflicts of interest in you undertaking this research? (E.g. are you undertaking research on work colleagues; or in an organisation where you are a consultant?) Please supply details.

The objectivity of the researcher is an essential value in any research project; it is the basis for any trust that may develop between the principle investigator and the research participants taking part in a study such as this one. I am aware that as a teacher currently working in the school that this study is based in there may be a conflict of interests, in terms of my role as a 'work colleague' for the staff taking part and as a 'teacher' for the parents who may agree to participate. To date the staff and parents I have spoken with informally have all been extremely supportive of this project, and the general consensus within the school is that this study is long overdue and a valuable contribution to the work we are doing with the students. I have a strong working relationship with the parents and staff in the school and have been involved in this type of exploratory work, examining issues within the PSHE curriculum many times over the past eight years. In this time I have developed a strong rapport with the parents and my co-workers and feel that they would be extremely supportive and willing to take part in a study such as this one. In fact one of the reasons that I have designed the project in the way that I have is because I have often run both large group meetings and 1:1 meetings with parents and staff with a high degree of success and the feedback I have received has always been very positive.

In order to ensure that any form of 'power imbalance' does not develop between myself and the participants I intend to develop an ongoing dialogue with the participants around four key issues:

1. My style of interaction

2. My management of the group meetings

3. My management of the 1:1 meetings

4. My planning & Preparation

Through imbedding this practise within the monthly meetings throughout the duration of this project, I hope to be able to identify any difficulties between myself and the participants and the general management of this study as they arise.

10. What are the expected outcomes, impacts and benefits of the research?

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Through this study I hope to challenge assumptions, to find out whether behaviours that appear to people who are neurotypical to be sexualised, necessarily carry this meaning for the person with autism. I want to identify 'ways of being' that will help others to interpret more accurately the behaviour of people with autism, so that appropriate rather than punitive support measures can be devised in relation to ' sexualised' behaviours. I would also like to evaluate whether this phase of 'sexual development can be an understandable experience for those young people within the study group. Essentially, I want to identify whether 'sexual exploration during adolescence' for the study group can be understood in the same way that it can for the neurotypical majority, or whether we need to achieve new understandings of these behaviours.

Lifeworld is a methodology that currently excludes people who do not access typical forms of communication, It relies on participants being able to report back about their personal experiences and provide 'meaning' to their actions, which is something the subjects at the centre of this study are unable to do. This study will explore using the people that presently exist around each of these students (parents, family members and staff) to act as interpreters of that meaning. In this adapted form those who know the student well can be called upon to act as expert guides to understanding and advocating the student's perspective.

Within this study the student's behaviour is seen in itself as a 'communicative act' and parents, key family members and school staff are frequently better placed than external researchers to interpret this. In this sense then it is very much the boys who play a central role within this study as it is this target group who are providing a large amount of the data and information that will be interpreted by the other participants involved in the project who will be acting as expert interpreters and guides. For the subjects, their level of participation is completely passive, there is no structural change to their home/school routines and they are required to do nothing more than simply be themselves at home and at school. The role of the participant interpreters [the family members and the staff] acting as 'expert guides', will be to provide their personal interpretations of what they believe the boys individual 'experiences and behaviours' mean and what they represent, for the boys. I accept that the interpretations of the subject's behaviour given by parents and staff might differ significantly from the student's actual perspective and I am not suggesting that parents and staff will always be an accurate voice of the student participants. However, it is likely that they would

be a much better informed and much more practised interpreter (Hodge et al 2010), and will provide a more reliable interpretation of the communicative acts of the boys within the target group.

The students are therefore both the primary data source and the central participants in this study. They supply the communicative acts from which the team that presently exists around each of these students (parents, family members and staff) will attempt to extract the meaning from. Through this process the students become empowered, as the research focus is shifted not towards what others believe the behaviours to mean for them but what the 'behaviours' and 'interactions' represent as communication attempts from the students. Through using this adapted form of Lifeworld the students 'perspectives' and 'personal agendas' will I hope become identifiable.

Possible questions that could be generated through this study may perhaps centre around how viewing and interpreting 'sexualised' behaviour' from the 'autism perspective' could possibly lead to the development of more 'pro-active' and less 'reactive' approaches to Sex and Relationship Education and the management of different forms of intervention around complex sexualised behaviours? It may lead us to ask what roles do power, control and normative interpretations of 'being' play in the 'management' of the sexual identity of disabled people? And what changes occur to the management of behaviour if 'sexualised behaviours' are reframed as an intricate personalised 'new' physical vocabulary, that both the young person and those who work with them can take part in and learn from?

11. Please give details of any plans for dissemination of the results of the research

The completed work will be made available within the school in the form of a completed bound document. All parents and staff will be given the opportunity to view the completed work and a central copy will be added to the school library. The final complete study will be the property of the University and a copy of the completed work will be added to the work held in their research department.

The work will be presented **to the staff, family members and friends** who have taken part over a series of workshops around the same types of topics listed above, in order to allow

those who have participated the opportunity to discuss and talk about how this study may have assisted them or provided them with some form of new understanding around the issues related to this subject.

SECTION C

RISK ASSESSMENT FOR THE RESEARCHER

1.   Will the proposed data collection take place on campus?

       ☐☐   Yes   (Please answer questions 4 and 6 only)

       X☐☐   No   (Please complete <u>all</u> questions)

     * No - data collection will take place in the researcher's school

**2.   Where will the data collection take place?
        (Tick as many as apply if data collection will take place in**

    multiple venues)

       ☐☐   Own house/flat   ☐   ☐Residence of participant

       X☐☐   School   ☐   ☐Business/Voluntary Organisation

       ☐☐   Public Venue (e.g. Youth Club; Church; etc)

       ☐☐   Other (Please specify) _____

3.   How will you travel to and from the data collection venue?

       ☐☐   On foot   ☐☐   By car   ☐☐   Public Transport N /A

       ☐☐   Other (Please specify) _____N / A_____

     Please outline how you will ensure your personal safety when

travelling to and from the data collection venue: N / A

4. How will you ensure your own personal safety whilst at the research venue?

My personal safety during this research is at this point not an issue as the level of risk is minimal, Parent, staff or student consultations / interviews that may take place would be incorporated in the school day and would not be viewed as presenting any extra risk above and beyond what would be expected in a typical school day.

5. **If you are carrying out research off-campus, you must ensure that each time you go out to collect data you ensure that someone you trust knows where you are going (without breaching the confidentiality of your participants), how you are getting there (preferably including your travel route), when you expect to get back, and what to do should you not return at the specified time. Please outline here the procedure you propose using to do this**:

All interviews will be conducted in school

6. **Are there any potential risks to your health and wellbeing associated with either (a) the venue where the research will take place and/or (b) the research topic itself?**

X☐☐   None that I am aware of

☐☐   Yes (Please outline below)

7. **Does this research project require a health and safety risk analysis for the procedures to be used? Yes /No**

If YES current status of Health and Safety Risk Assessment.

I confirm that this research will conform to the principles outlined in the Sheffield Hallam University Research Ethics policy.

I confirm that this application is accurate to the best of my

knowledge.

Principal Investigator's signature	Thomas Andrews
Date	13 / 01 / 10

Supervisor's signature (if applicable)	
Date	

Appendices 6 - Subject: Arran: Example 1 / Transcript extracts taken interviews with Parent E

Excerpt: Transcript 1

Parent E: Yeah, both him and his brother started to work out where was ok, and not ok and for both of them now their bedroom is their private sanctuary, sometimes in the morning, him and his brother just stay in that room doing whatever they are doing, they're so tight with each other, we aren't really allowed in and sometimes have to let the [school] bus go, cos neither of them will come out. But for Arran if he doesn't have to go anywhere he likes to be in that bedroom for half a day – and then when he emerges its usually when he wants some food, and he kind of gets up and comes upstairs in his own time, he's not really much of a morning person – so I think that space down there – that's when he has that time for himself – where he can masturbate or whatever he does. I have actually walked into the [bed]room, when he has had the cover up hiding whatever he is doing, with just his head peeping out, and he'll just look right at me - and you can tell he's having private time. He kind of just stares kind of blank like he knows he's been caught. I don't know, erm...and he knows that its fine because that's his area – it's not the kind of – you know I wouldn't keep bursting into the room every 10 minutes, I'd just leave the boys to get on with it down there and then they'd come up unless it was a college morning and then obviously then I have to go and get them out of bed and get them ready...I mean he never jumps up out of bed, you know Arran...you've got to coax him, I mean he knows he's got to get up when the bus turned up we'd just have to wait until his was ready to leave his room, and he would only come out when he was ready – but you've got to give him time and it might take 10 minutes before he actually gets out of bed but he will do it eventually- but that room is really there space really, and that's their private space – that is the place where if there is anything physical or sexual going on for Arran it's in his bedroom and occasionally I've had to go into his room and he has the covers up to here [his neck] and his hand are going [moving up and down] under the duvet. So I just pretend that I haven't seen him, get what I need and leave. He just didn't like anyone coming into his bed room, that was totally his space and we just had to respect that, I mean why get him all stressed out, he's such a softie at heart.

T: Would he do that anywhere else in the house, because he had done it in the past right?

Parent E: Yeah for a short while and then he cottoned on quickly, mainly through our reactions – especially his sisters, 'shrieking' can you imagine by then, you know teenage girls, and he probably thought hello what's going on here – because they probably hadn't had that reaction to anything he had done before – the funny thing with Arran though is he has certain other habits, which are really horrible, like he'll drink out of his cup and then spit it back in again and we'll be like 'Arran, that's disgusting please don't do that again' – but he'll still do that sometimes just to please himself but obviously he knows that that's not as taboo as the sex thing.

Excerpt: Transcript 2

T: Well then, do you imagine him having some form of sexual life that may centre exclusively around himself, maybe involving masturbation.

Parent E: I have actually walked into the [bed]room, when he has had the cover up hiding whatever he is doing, with just his head peeping out, and he'll just look right at me - and you can tell he's having private time. He kind of just stares kind of blank like he knows he's been caught. And like I know that he does it and I'm glad of that – because I just think – he's in tune with himself, and we all need to be in tune with ourselves really don't we – and that's also a side to everybody that it's nice if it's fulfilled in whatever way do you know what I mean – in whatever way we find – which suits us – I think that's it really, why he's so nice and laid back – you know it probably helps – especially with a lot of young men that have got a load of testosterone you know at a certain age and erm...you know normally they'd be at the height of their sexual prowess – you know – with blokes when they are quite young it's sort of when they are full of all their hormones – but you know – it'd probably be quite damaging if he wasn't able to fulfil that side of him and that would probably lead to frustration.

T: How do you think he has found out how to masturbate?

Parent E: I think just through self discovery on a physical level – in the same way as he's probably found out other things about his body that he likes doing on a sensory level, because you know they're like experts 'autistic people' in like...sensory things...things that we probably, because we're busy going on with our everyday lives – but they've got all the time in the world to find out what turns them on – the tastes they like – the things they like to feel – so I can imagine on a sexual level that's another extension of that, it's just another lovely

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sensory thing and a lovely feeling – but they've realised with this particular one the difference is the whole taboo with society of anything to do with your nether regions

T: Do you think that Arran has picked up on that being taboo from somewhere?

Parent E: But also if you think about it going to the loo is another thing – like when you have to use the toilet, you don't stand out in the street and do a wee in front of everybody because that area is – you know – so I think he must have a sense of that area being something that's like oh you don't do it there....

Further on in the same extract

T: So what do you do, you know to help him?

Parent E: As I've said in the past to simply 'let him be', you know let him do his own thing, don't get in his way, and give him a certain level of respect, you know on a practical level, allow him a bit of space and that's really the only way that I can describe how – you don't really sit there thinking 'how am I going to support me sons sex life' – I mean he's never going to have a partner, it's just not going to happen – maybe if you've got someone out there doing things say like my older son [G] who is also autistic who is different to Arran , but right now those two they are very much about their room, they simply won't come out of their room, sometimes all day, till they are hungry, sometimes it slows the whole day down'. So we've just gone, OK. But I don't ever think oh what are we going to do, get em out of there, get em to do something, I mean him and [G] they just do their thing, they stay in that room, they mope around, sometimes I do think what would have happened if...but...[G] he'll never have a partner because you never know, he moves around outside in social settings and he relates to people differently to Arran, But For Arran, I don't think he'll ever sit there and think in the same way that we do – like oh I'd like a girlfriend or whatever – I don't think he sees the world in that way. For him he's happy to just chill out, with his stuff in his bedroom.

Further on in the same text

Parent E: So going back to what you'd said earlier, it's all about giving him space and letting him do his thing and letting him come to people when he wants to, At first I was like 'oh god' you know, he's decided he wants to opt out and he's not co-operating, but then I looked at it

in a positive way and he's realised that he has got some control'. I mean he aint got a lot of control, so I just went along with it, so great he's found something that he really likes doing and something that he's in control of, in the sense that he can let go when he wants to.

T: would you say to somebody these are the two ways we can help to support him in developing some kind of sexual identity or just a way for him to interact with people that is pleasurable on another level for him

Parent E: Well, you know like I told you before, Arran and [T] his sister are close close close, Arran has developed a new type of relationship with his sister, its lovely to watch, they are close but it's wholly their thing, they watch certain things on the TV together, they have their own little spot on the couch, they even have their own private form of Makaton, no one is allowed into this and this has happened really over the past couple of years'. We can't get near em' and I'm just pleased that he has that, that he has the closeness, I mean they've always been close but now they are like, dead close.

Transcript 3

Parent E: No, that wasn't actually there, that was at my mother's cottage – it was by the curtain, by the French doors – he thought he was being private – because he was laying by the curtain and the curtain was a little bit over him, so he'd kind of made his own little screen. Spaces are very important for Arran and wherever he goes – you've got to allow him to find his space – that is 'the best place for him' – you know he likes to be either on the periphery – but you know he's not one of these people that likes to be totally away – like when he's down in his bedroom he requires his own totally private space 'If he looks like he wants to stay in that room longer, if I go down with his tea he'll just shoot me a look that means - could you please leave me alone. Cos like with Arran it's all in the eyes, we look at his eyes and we know exactly what he wants, and I feel quite privileged when he does that because he has chosen to let me know, and then when he is ready he'll go back to what he's up to.

T: What's the most private place in this house?

S: Probably – on a sexual level, his bed, that is definitely the place – like he would never [touch himself inappropriately] if he was up here or around anybody else. Maybe when he was 10 he may have but it was around that time that he was learning what was and wasn't

appropriate around People, but now...he just spends a lot of his time in his room, you know,

touching himself, and we've just got used to that and we let him do his thing in his own time.

I know what he's doing in there, he's masturbating, I see it on his sheets.

Appendix: 7 - Subject Chris - Example 2 / Transcript extracts taken interviews with Parent C

Excerpt: Transcript 8

Parent C: What I have noticed of recent - Chris is a very early bird and he will get up before everybody and he hasn't quite got the idea that on Saturdays and Sundays we're all entitled to a lie in if we haven't made any arrangements, so he's up really early which is fine – and I've kind of learned to live with that. But I've noticed a couple of times that he's gone into his brothers bedroom, when his brother has been asleep and his brother sleeps deep, and he will sit on the edge of his bed, and he will – I've noticed I've come in before and he's run out and he's taken the quilt up off of his brothers feet, and I think he is aroused by feet, the touching of it, I don't know if he rubs himself on the feet, but certainly feet is a thing that he finds arousing. Now, like his brother's feet have become the be all and end all of his life, and he is always trying to get to them somehow, his brother's aware of it and we joke about it, but for Chris it's very real, d'you get me, like proper real.

T: How old is his brother?

Parent C: His brother is [x] and he is oblivious to it because – nothing - and I haven't alarmed him to it because I don't want him to feel awkward about it...understand ...understand what's inappropriate what can happen what should happen. So I haven't alerted his brother to it, but when Chris has heard me approaching he has darted out of the room, so I know that something is going on, I don't always hear when he goes to do it or why he continues to do it, but it is evident that he s doing it.

T: Do you think there may come a time in the near future when you will have to speak to your others son about this.

Parent C: Oh most definitely, yes

Further on in the transcript

T: Ok [D] so let's start with the first point, in your opinion do you think that Chris has some form of 'sexuality' and that of course could take any form.

Parent C: Most definitely, Chris certainly has a sexuality and he hides it from me, there was a classic actually just a couple of weeks ago, Chris came down from his bedroom, I was in the kitchen preparing his lunch and he was still in his Jim jams and a t shirt and I noticed that his jim jams were wet, that they were saturated, and he does not have accidents like that, he's been in control of his bed wetting from a very early age despite his disabilities and – so I went towards him and looked at it and then I touched it and I thought well that doesn't actually feel like urine. So, I said to him "Chris do you feel ok" and he had this blank look across his face, so I looked at it and investigated further and realised that he'd obviously masturbated and he had ejaculated, but with regards to that he didn't know what to do or where to go – so he didn't change his clothing, he just kept his clothing on. So immediately I said " it's ok it's ok". I told him to take his Jim jams off, to go and have a shower and gave him a new set of clothes to put on and he was fine – but, I could not identify what had aroused him, when, how, Cos I was downstairs and he was upstairs – and he just appeared and had finished his business. To be honest 'I think it [masturbation] vents off the steam, and I think...yeah...otherwise he wouldn't engage in it. So, yeah I feel that he feels that that needs to be done and that this is the route to get there, so really he's achieving the aim that he is trying to achieve, 'I need to let off some steam', 'I need to ejaculate', 'I need to touch myself', 'I need to feel ok', 'I need to release'. I think it makes him feel that he has achieved a sense of release. Cos there's no doubt that Chris has got stresses, you know with regard to being understood and with me understanding him, and his frustrations and all the rest of it. Trying to talk and not being able to form the words, trying to sing but not being able to form the lyrics, you know...so there's got to be some kind of pent up feeling and every so often – if this is his release – then I think that he feels - 'yeah great"

... Parent C: Another thing is this, Chris has tried the rubbing of the feet, I mean if I've got my jim jams on or my lounging about in the house trousers on, Chris has tried in the past to lift my...it's kind of feet and knees...lift my trouser leg up and try to touch my knee and touch my leg. And initially and I couldn't say when he started to do this, I thought he was just playing around, he's interacting and obviously I'm going to engage in that, cos there's so much I want him to do and I'm keen for him to exercise any voice that he does have cos right now I don't

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think that he has a voice as such, well...not a voice of words. So, then I noticed the more that he was doing it the more he was becoming aroused, so I wouldn't brush him off or shout at him or anything cos it's not that that is a bad emotion to have, cos it's a naturally fantastic thing to have...

T: So you wanted him to experience it [intimate contact] but positively?

Parent C: Absolutely! And I didn't want him to get stressed, although I am aware that I was the subject of what he is doing, and it's really difficult to say, well 'yes son I want you to be able to experience this thing cos it's a beautiful thing but you can't experience it with your mother'. So, well first of all I was really shocked, but you know...he doesn't seem to do it as much, he will try but when he does try to go back to doing that I just say "Private"...and Chris understands that completely. And I've done that before him and he has taken himself off into the utility room and I don't disturb him I just let him get on with whatever he is doing. And he understands that and he responds to that, erm he has tried to do the same thing with my step mother and with regard to 'touching her feet' or 'lifting her skirt as she walks away' and I'm like, 'Chris you're dread'! [laughs]. But and again I don't want him to feel that he shouldn't feel the way that he wants to feel and I don't want to suppress that at all, but I really don't know how to convey best to him who he can do that with. But it's true, I've seen Chris look at me and sometimes he'll put his hand out as I go by just to make contact with me, and I'll have to give him a look to say – don't even try it mate. Cos I know what he's thinking.' Because Chris doesn't have a circle of friends, he just has family members. But you know I don't want him to think that it's a bad thing cos it aint a bad thing...

Transcript 9

T: How would you go about having that kind of conversation with Chris?

Parent C: That's the difficult thing, I don't know how to approach that subject with Chris, I never let him feel that what, when I've seen him with an erection or when I've seen that he has masturbated, you know it's evident in his bedroom on his sheets when I change the bed linen that it has taken place, but I never make him feel that that's the wrong thing to do, or that it is bad, but I am struggling with myself really how to express to Chris, that 'yes' it is ok, but when it is appropriate and when it is inappropriate, who it is appropriate with, etc etc,

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what kind of format – I struggle with that myself as a parent how I relay that to Chris, but 'I mean sometimes when he has come in, in the afternoon, if he's come in when I'm not here – and I've gone up to let him know that I'm here, I will get the resistance where he is pushing back the door [to his bedroom] to keep it shut'. But, we can go in there at other times for sure, but we all know that there are times when we definitely can't. That's when I know he's like, playing with himself, then it's like you gotta keep out, and I respect that, don't know where it's going but I respect it, what else can I do.

T: Has Chris ever masturbated in front of other people?

Parent C: He has never done it, ever...he has never touched himself inappropriately in front of family members or when we have been out, no.

Further on in the transcript

Parent C: That thing I told you about, about his brother, yeah and about Chris goin into his room right, well I put a lock on Brian's [Chris's's brother] door, cos Chris was going in there and standing there staring at Brian's feet, we didn't really know why. But I felt that he was displaying what I saw as a sexualised behaviour - in that way maybe I'm wrong - who knows, but I've got to teach him somehow, I know that and I had kind of given him to much freedom around that room, so now it's locked and he knows, he knows that I know, that's how it is between me and him.

T: So would you say that from that you could project that he has some sense of what is ok and what is not ok behaviour?

Parent C: Yeah, to a degree, I guess he obviously does know that it's not ok to be around by his brother, but I guess he knows it's not ok to be touching himself publicly when we have a family gathering, or when we've gone out shopping.

T: What about when he becomes sexually aroused by his brother because that sounds like a potential situation, would you agree with that?

Parent C: Yes I do, but he obviously doesn't think it's inappropriate, so he'll continue to do that, and the mere fact that he is doing it without me knowing, and is progressing from his

room to his brothers room, to perform that act for the want of a better word, I guess he knows that to a degree it's not right, erm, I might be wrong he might think it's ok.

T: You know it's not unheard of for some young people with autism to develop parallel relationships with members of their family, which they describe as in some way 'intimate', not sexually intimate and wholly appropriate, but that they represent something else.

Parent C: The thing is when his brother is awake he never tries it - never. They play football together they interact together, they have a standard brother brother relationship. But when his brother is sleeping and Chris feels that he has the need he will try it on. But not now [laughs] cos that doors locked!

Appendix 8: Mahmud - Example 3 / Transcript extracts taken interviews with Parent D / Subject:

Excerpt: Transcript 6

Parent D: Mahmud has his routine, he comes in he goes up to his room, no problem and that is it, he would come down to eat, I'd just call him from the kitchen and he'd come down but now that room is his – haven – it's right at the top of the house just opposite the bathroom. My son [Mahmud's cousin] was in that room, cos although we've got this new place we still haven't really got that much space, not with the girls and the rooms are small. So we need those rooms, my son needed that room, but now Mahmud won't let anyone in there.

T: When you say no one, do you mean absolutely no one?

Parent D: yeah, I can't even change his bed linen sometimes, I have to do it when he is at school or at Lough road [respite centre].

T: How long has it been like that?

Parent D: Six months.

T:Wow

Parent D: We know not to go near his room now, before it was ok to go into his room, he even shared that room with his cousin, but now – no. He guards that door and gets stressed if we go near it. We've just picked up on it as a family – the room is out of bounds, simple as that. It's tough on his cousin though, he's got to sleep on the couch now or he sometimes sleeps in his little sisters room.

Further on in the transcript

.....Parent D: With this room thing, it's got so that he needs to be in charge of all the doors in the house, all of them. If the postman comes or like when you came to bring his bag back last week and he was upstairs, when you rang the bell he got very stressed, cos the front door was gonna be open and that is stress for him now, that's why he shouted. And the neighbours are asking me why he keeps shouting. What can I say? It's something that he does now. He's got to be in control of the doors, especially his bedroom door – we don't know what to do

about it! But if we shut the door or move it before he has finished shutting it in the way that he needs it to be shut, that's a big problem. That's why we couldn't invite you in. Because you aren't meant to be here in Mahmud's mind, do you get me? And if you had come in then he would have to sort out the door, and you. Cos that's the other thing, people in the wrong position and doors, it's tough.

Further on in the transcript

Parent D: This putting people in places has got nuts, now for Mahmud everyone's got to be in the right position sometimes, this has got worse as he's got older, sometimes it's too much' it means anyone who comes round who doesn't know him, well to be honest we don't have guests come round anymore, it's just too difficult. I'm worn out, we all are....

Transcript 5

Staff F: I've known Mahmud for a long time now, I know his family and I've walked back to his house with his aunty loads of times with him when he aint got on the bus and he is always always alright with me.

T: But what about that thing you mentioned last time we met, you know that time when you were in the corridor with him.

Staff F: Oh yeah, well he's getting really grabby now, he's grabbed [P] and that was a right shock for her cos she's like his mum you know, and he'd never have done that when he came over from the primary. But he's so big now, and he's lanky like you can see he's gonna be proper tall. But yeah he grabbed me.

T: How'd he grab you?

Staff F: He grabbed me boobs, well to be honest Mahmud has grabbed my boobs a few times, he will look at me, then my boobs, then squeeze them, now that's something he didn't used to do before and he knows he shouldn't. Sometimes if I'm in the room with him I know all he wants to do is touch me and like it does make you feel a bit uncomfortable.

T: Do you think it makes him feel uncomfortable?

Appendix 9: Subject Min - Example 4 / Transcript extracts interviews with Parent B & Staff:B

Excerpt: Transcript 6

T: What makes Min stressed?

Parent B: What makes him stressed?

T: Yeah does he get stressed at home at night, when he's in his room, he has a room of his own doesn't he?

Parent B: Yeah?

T: Didn't you tell me that he was starting to get a bit more aroused or that he was becoming more difficult when you bathed him or put him to bed.

Parent B: Min is more anxious, especially when I am washing him or bathing him or when I change him in the night, I can remember when I could just relax with him, but now I can't, he's more anxious around me, he is becoming a man and I am really struggling with it.

T: What other time of the day is difficult for you now?

Parent B: Every night now when I go in to change his pad I notice that there's stuff in it [semen], like he has been playing with himself in bed. The first time I was like, oh, now it is like all the time.

T: How do you handle that?

Parent B: I have to get up every night anyway to check on him and cos I can never really sleep anyway, I have my mum in the front room and the other two in with me so I am always kind of awake anyway, so I just always get up anyway. But I have to clean it up and sometimes he is awake then and won't go back to sleep, and then that's it really.

T: that sounds tough

Parent B: I don't even think about it anymore, I just get on with it, but it is on my mind all day, like another night.

T: can our mother help at all?

Parent B: No, she's old

T: Neighbours?

Parent B: No Min, makes so much noise the neighbours hate us

T: Ok

Parent B: We need to move but I don't have enough points

T: Maybe we can do something about that.

Transcript 2: Staff B

T: So from what you are telling me Min doesn't appear to want to interact with anyone unless it is on his terms, what do you think?

B: Well yeah...but what I think is difficult as well as that, well we're a school after all, and you know we can't, I mean Min is a 1:1 so he will ideally always have somebody working with him, And he needs 1:1 – what I'm saying is that Min is very complicated and he is always looking to hit out, so really the other kids don't get a choice around who to work with he kind of takes over a bit, and personally I don't think that's fine, I don't think that he should get a choice of staff, that's not the way a school should work...and...but...it means that he is mostly with staff isn't he? And he's taking liberties now and is starting to touch kids, is that right?

T: Well we've given him the opportunity to spend time on his own and he hasn't touched anyone. But really we were simply practising 'ok touching' without spatial management of the students...

B: Well I think that's the point that I was making, I mean peer interaction doesn't happen much because I think a lot of our students do not have a member of staff working closely with them for safety reasons, and that's why I think a lot of students kind of don't like Min, well I mean they're not going to build relationships are they....I mean you need a bit of freedom to build a relationship. And there is the idea of trust as well and it's difficult to enable that. To

enable peer interaction, you know with someone like Min – he doesn't initiate much, I mean how he is maybe going to make contact with another student, he doesn't even come forwards towards the staff [who he knows well] – what and he's going to go and make a connection with another student, I don't even see the other students being that interested in him anyway. Saying that though he you know he just likes to find that corner [in the classroom] and sit there, he may welcome you in, he may not, but he will let you know, and if it's a 'yes', then he'll bend forward and offer his head for a stroke, or he'll take your hand and place it on his head to be stroked', but a lot of the other kids are petrified of him, I see them they stay away from him. But I have noticed him doing that head rub thing, yeah, but he is still you know...

B: I have never seen that with A or with any of the other students doing that though. The thing is I just don't see him enough to know if that happens anywhere else.

T: Do you think it would be appropriate if the students had a separate space where they could develop [self touching / interpersonal connection].

B: Maybe, it depends, it would need monitoring.

T: Do you see Min initiating any other types of contact

B: Yes, but only with people he has chosen, and it is rare, he is very tricky, unpredictable.

Appendix 10: Subject Gerry Example 5 / Transcript extracts interviews with Parent A / & Staff: F

Excerpt: Transcript 4

T: Ok, [M] it's good to see you, ok so in this meeting, the focus of this meeting is going to be 'relationships', if you could just briefly start by telling me about Gerry and what you would describe as his behaviour towards people, you know, how does he connect with people.

Parent A: Well Gerry is 15 and he has recently become very aggressive and violent, this has become apparent at home and at school, and I have had about four meetings with [C] specifically about Gerry's behaviour and it has been universally observed [understood] by many people that this might be to do with Gerry's sexual behaviour. I guess it's not just me, but it's been forced on me and the potential changes, evidence that he has always played with himself – but has never ejaculated, it calms him, and we have always been rather aware [throughout his work at school and with his people here at home – I mean formalised by – telling Gerry that touching himself can lead to aggressive behaviour on top of the fact that it's inappropriate and that they should take him to the toilet – so that Gerry can have private time. But lately, boy, Yeah he's now very active and stroking himself hard all over and grabbing himself and gripping himself, and he's changing - actually he's going through a massive change. He's growing up isn't he, tell me he's growing up Tom [laughs].

T: It's fine [M] it's called being a parent [laughs]

Parent A: Lately there has been a huge huge change, emotionally, to the point where he has been extremely confrontational towards his carer, and that pretty much ended that relationship... So yeah, Gerry's relationship with his carer completely broke down, they'd been what I would say was very close, really close and safe, but then there was a huge change, emotionally, to the point where he was extremely confrontational towards this carer, and that pretty much ended that relationship', she had to go and she'd been with us and Gerry for a long time, now we've got [A] back in the other house, but it has changed things for sure...lot of change going on in this house right now Tom. It has all had an astronomical effect on that 'caring structure', that's gone.

Pause

Parent A: And you know I have been asked by various behavioural therapists to use certain communication[s] too support him in the toilet, but he urinates on them....and I've been told to label any attempts at masturbation, to direct him into the toilet, or into his bedroom and formalise it in that way. So, in a way I have been alerted to this change, I have more experience of it than ['J' husband]. But I don't know.

Further on in the transcript

Parent A: At home, I suppose we've always been very, perhaps to relaxed about it [nudity], we see it as a natural thing, you know he's been around in the morning when I've been showering, or on the toilet, ...so, then it happened. And now, often what he'll do now is he'll just come into our room naked and like, masturbating, and I can tell you, this is something we hadn't expected and for us if I'm honest - it has become a big big problem, and one that we are currently struggling with. Sometimes we simply don't know what to do. And our room and the bathroom is the one we all share and he has always just walked around down here, it was lovely. So in the bathroom while I'm in and out, you know I get dressed in the morning, he comes down then, and I don't think our behaviour has changed at home, with relation to that, our behaviour has changed in terms of labelling it.....and in....trying to use the same terminology and trying to encourage him to go to his room or to the toilet – providing labels for his bedroom and other areas of the house, but it's tough.

Further on in the transcript

Parent A: ...Hurrah! puberty's here, and do you know what he has a thing about his legs – especially shorts in the summer, now that can be a problem in the summer, anybody who wears skirts. In fact when [J] has come back with friends form college it can lead to difficulties, because he likes girls, he changes when his brother brings girls home, it's exciting for him he gets excited you can see it in his face. And they love Gerry, they always make such a show of him, he sits on the girls laps and gets really excited... he does this thing with his hands [a gesture which entails Gerry linking his fingers together and pulling his hands towards him tightly] and I've said to [J] that's ....Gerry's sexual advances....

T: Did you ever think that this would occur.

M: No I knew, I mean he'd already begun to appear more 'man' like, and for me this just confirms what I already thought, he's absolutely changing into a man.

Transcript 8: Staff F

T: How do you think Gerry uses certain spaces?

Staff F: Well generally, he's fine and he'll just stay in here with us pretty much every lunch time, he likes the lights off and he just potters about with his ball of cloth [Gerry tends to wrap his right hand tightly in a large ball of cloth that he keeps on his hand all day].

T: Where does he go if he wants some private time then?

Staff F: Now, he will go into the cut out room and play with himself and you know what sometimes we can't get him out of there, and when we try he gets very stressed, it's a nightmare. Some people won't even try to get him out, they're scared.

T: Who allowed him to use that room for that?

Staff F: No one, I think, he did, he's just taken over that room sometimes, if the lights are off and the room is like quiet he'll be straight in there, you can't get him out, and no matter how sneakily you peak in, your eye will see his eye looking right back. It's like he knows that you are watching him and he's like watching for it. Won't come out though.

T: So what do you do when the kids come back up from play?

Staff F: We call for Amanda.

T: Then what happens?

Staff F: he comes out.

T: Why do you think he comes out for Amanda but not for anyone else?

Staff F: Cos, Amanda works with Gerry in a way that nobody else can, she knows him inside out and he trusts her totally, when he's in a crisis you call for Amanda, because he won't calm down for anyone else. They know each other well, he trusts her and let me tell you he don't trust a lot of people.

Appendix 11 – P Level Indicators

P3 Indicators

- Pupil directs communication towards adult to gain attention and for physical contact. E.g. by vocalising, reaching out or making eye contact.
- Pupil is able to make choices and will request preferred activity by using some form of vocalisation or indicating towards preferred object.
- Pupil begins to explore objects as tactile cues to events or activities.
- Pupil requests events or activities e.g. may point.
- Pupil explores materials in increasingly complex ways.
- Pupil indicates when they are uncomfortable e.g. cries or gets frustrated when wet.
- Pupil may begin to communicate intentionally. They seek attention through eye contact, gesture or action.
- Pupils may use emerging conventional communication. They greet known people and may initiate interactions and activities.
- They may respond to options and choices with actions or gestures, for example, by nodding or shaking their heads.
- Pupil may communicates spontaneously and intentionally through facial expression, gesture and emerging vocalisation

Appendix 12: Pen portraits of the Research Subjects

Here are five pen portraits of the research subjects involved in this study, the identities of the subjects is protected by the use of pseudonyms.

Min

Min is a 13 year old young man, he is physically quite small and with what has been described as rather a shy nature – he is a Londoner of Chinese heritage – he has a clinical diagnosis of Autism with Severe Learning Difficulties – and he currently lives at home with his mother [a single parent, English is her second language and she is unemployed and his primary carer], at home there is also his younger brother and his two grandparents – and the five of them live in a small two bedroom council flat – he sleeps in the same room as his mother but in a separate bed – currently he is bussed into school every day from his home in a secure harness and he requires 1:1 support both on the bus and in school - he is currently described as working at P3 in literacy and is not able to efficiently access typical forms of communication – he is often described by staff as 'sexualised and challenging' – he does not attend any after school clubs or receive any respite care at present either during term time of throughout the school holidays – outside of school his mother uses a wheelchair with him when going out into the community as he refuses to walk – he is padded and requires a high level of physical support around his personal care needs – Min enjoys sitting with his legs crossed and rocking whilst playing with his saliva, he likes music and sensory experiences that include a lot of rolling and rocking – he tends to spend most of his time at home and rarely accesses the local community - he has a pronounced callus on his right hand from continual biting and he will tend to hit out at people who enter his private space – currently his mother is struggling to support the family, as she has no other money other than her benefits to live on and she has not so far been able to access the type of specialised support that her son requires in order to support her at home.

Mahmud

Mahmud is an very athletic and extremely charismatic 15 year old young man – he is of Somali heritage who was born in Somalia - he has a clinical diagnosis of autism with Severe Learning Difficulties – he currently lives at home with his aunt [a single woman, who has English as a second language, who is unemployed and who is his primary carer], along with his four cousins in a three storey council town house – currently Mahmud is bussed into school every day from his home in a secure harness with 1:1 support on the bus and he requires 1:1 support in school - until quite recently he slept in the same room as one of his older cousins in a separate bed but this sleeping arrangement has broken down and he now has sole access to this space – he is currently described as working at P3 in literacy and is not able to efficiently

access typical forms of communication – he is described by staff as 'sexualised and challenging' – he does not attend any after school clubs or receive any respite care – Mahmud is a war refugee who had in the past experienced extreme trauma in Somalia and was a witness to attacks on his family – because of this he had received specialist 1:1 therapy over a 4 year period, provided by a psychotherapist from the Tavistock clinic – it is believed that the trauma he was exposed to has had a significant impact on the way in which he can often present – He tends to spend most of his time at home alone and rarely accesses the local community – he enjoys listening to music on youtube on his own and dancing [rocking from side to side with his arms held out stretched] – he prefers to be in control of the space he is in and can occasionally get quite stressed around this, when this occurs he will self-harm by slapping and hitting himself in the face with force – it is generally felt that he has made significant progress in coming to terms with his past and is growing as a person.

Gerry

Gerry is a happy and charming 15 year old young man – he is a Londoner of UK White English heritage - he has a clinical diagnosis of autism with Severe Learning Difficulties – he currently lives at home with his two parents in a large five storey house in the centre of London but he also has access to two separate smaller purpose built properties that are staffed by carers who work with Gerry throughout the year – He has an older brother who is at university and who also lives at the house out of term time - currently he is bussed into school every day from his home in a secure harness with 1:1 support on the bus and he requires 1:1 support in school – at home he has a large area in the basement of the house that is set aside specifically for him, and he is supported at home by a rotating group of support staff who work closely with the family and who are well known to the family through working with them over a number of years - he is currently described as working at P3/4 in literacy and is not able to efficiently access typical forms of communication – he is described by staff as [highly] 'sexualised and challenging' - he does not attend any after school clubs or receive any respite care but instead is supported by the team of staff around him hired by the family – One of the things that George likes to do is wrap a selection of cloths around his hands and he will choose from a collection of cloths that he has chosen which are then 'balled up' on top of his head and held in place by a strip of material [these are critical materials for George] - He has pronounced lumps on his forehead caused through hitting himself in the head with considerable force consistently throughout the day when he is stressed – he also has calluses on both of his hands caused by excessive biting of his hands when stressed.

Arran

Arran is an extremely friendly and highly engaging 15 year old young man – he is a Londoner of Black heritage – he has a clinical diagnosis of autism with Severe Learning Difficulties and he currently lives at home with his two parents, his brother and his two sisters – His brother is also positioned on the autism spectrum with a similar profile to Arran's and his two sisters both have a diagnosis of sickle cell anaemia – the family are often described by staff as very calm and relaxed and this is mirrored in Arran's general way in which he comes across to others – the family live in a basement ground floor maisonette and Arran shares a bedroom with his brother – Currently Arran is bussed in every day in a secure harness with 1:1 support on the bus and requires 1:1 support in school - he is currently described as working at P3 in literacy and is not able to efficiently access typical forms of communication – he has recently started to exhibit behaviours that staff are describing as 'sexualised and occasionally challenging' – he attends after school clubs and respite care at the weekends and in the school holidays – Arran is extremely sensitive to noise and to being touched and this has led to him harming himself quite considerably in the past, causing hard calluses on his hands brought about by biting – Arran has formed what have been described as extremely strong bonds within his family and with the staff who support him at school and at home – at home he is working on an ABA program and has a group of ABA trained support staff who have worked with him over an extended period of time – Arran has a great sense of fun about him and enjoys music, dancing and watching youtube videos.

Chris

Chris is an extremely strong willed and fiercely independent 16 year old young man – he is a Londoner of Black heritage – he has a clinical diagnosis of autism with Severe Learning Difficulties and he currently lives at home with his mother [a single parent who works full-time], his brother and his large extended family – Home is a large four bedroom house in West London – at home he has his own room – When Chris was a child his father passed away and it is generally felt by those around him that he has never fully had this explained to him - Chris comes to school every day in a taxi with an escort – however there are days when his mother has to bring him in as he can occasionally not manage the transition from home to the taxi in the mornings - he has a clinical diagnosis of autism with Severe Learning Difficulties and he is currently described as working at P3/4 in literacy and is not able to efficiently access typical forms of communication – he has recently started to exhibit behaviours that staff are describing as 'sexualised and occasionally challenging' and these behaviours are mirrored at home – he does not attend after school clubs and respite care at the weekends and in the school holidays and tends to be cared for by his extended family – On occasion Chris can often be highly physically oppositional towards others, and this has led to him often being held or taken to spaces where he is given time to calm down which has in turn led to a lot of stress and tension for him – Chris does not tend to handle these types of situation well – He spends a lot of time on his own at school and is 'always' outside of the class – Chris is always

fashionably dressed, and his mother has made a point of exploring this as part of his journey into being an adolescent.