ANGLIA RUSKIN UNIVERSITY

FACULTY OF SCIENCE AND TECHNOLOGY

INTERACTIONS INVOLVING PEOPLE WITH SEVERE INTELLECTUAL DISABILITIES

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A thesis in partial fulfilment of the requirements of Anglia Ruskin University for a PhD in Psychology.

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ABSTRACT

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People with severe intellectual disabilities usually have few formal language skills, may not be able to produce or understand speech because of their developmental level and, as they communicate in idiosyncratic ways, carers may have difficulty recognising and interpreting communication. There is currently little known about what interactions involving people with severe intellectual disabilities actually look like. Because of the lack of previous research, an exploratory approach was used to examine this over-arching research aim.

Approximately 40 hours of video data of everyday interactions between care staff and people with severe intellectual disabilities were collected from one residential centre and one day centre in the South of England. The main analytic approach used is conversation analysis although ethnographic notes were also made and are drawn upon throughout. At times, other methods are also used.

Themes emerged from the data and are 1. Vulnerability 2. Relationships 3. Resistance and 4. Meal-time interactions. It is suggested that:

1. People with severe intellectual disabilities are vulnerable but are often viewed as *only* vulnerable. A holistic view should be taken when considering risks in the lives of people with severe intellectual disabilities.
2. Close interpersonal relationships can exist between care staff members and people with severe intellectual disabilities and these are demonstrated through their actions. Such relationships should be acknowledged.
3. People with severe intellectual disabilities may resist activities in a number of ways. Ideally staff should acknowledge and respect signs of resistance. Making people as mobile as possible may help to promote independence.
4. Meal-time interactions require co-operation between people with severe intellectual disabilities and care staff. People with severe intellectual disabilities can be active players within these interactions and this should be encouraged.

It is also suggested that people with severe intellectual disabilities may be capable of making some decisions which affect their wellbeing. This is in contrast to a current specifier in the DSM-5 (APA, 2013). Practical suggestions for care staff are also provided.

Key words: severe intellectual disabilities, severe learning disabilities, communication, interaction, resistance, meal-times

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Copyright Declaration

1. Navigating the Thesis

In this thesis, a brief overview of the current research, examining interactions involving people with severe intellectual disabilities and an overview of the political landscape is provided in Chapter 2. Additional literature relating to topics which are addressed in later chapters are introduced, summarised and drawn upon at "strategic points throughout the thesis" (p.2, Kent, 2011). Specifically, guidance relating to the Mental Capacity Act is covered in Chapter 4 and literature relating to the principles of Conversation Analysis (CA) and its use in atypical populations can be found in Chapter 6, with considerations for ethnographers being provided in Chapter 7. In Chapter 8, which is a conceptual chapter, and Chapters 9, 10 and 11, the analytical chapters, topic specific literature is outlined in sub-sections within the chapters and, where appropriate, drawn upon within the analysis itself.   An overview of the contents of each following chapter is provided below.

Chapter 2 – Introduction and Overview of the Literature

In chapter two the topic of the research is introduced. Key terms are defined, and the political background described. The general background literature is summarised.

Chapter 3 – Procedural Methods

The procedural methods are outlined in this chapter.   The research protocol, recruitment process and details relating to data collection are provided.

Chapter 4 – Mental Capacity Act

Ensuring that the research was conducted ethically and approved by the appropriate regulatory body was a large part of this project. This chapter provides an overview of the ethical considerations necessary to complete this research, particularly those relating to the Mental Capacity Act (2005).

Chapter 5 – Participants

Here information relating to the participants is provided. For participants with severe intellectual disabilities this includes details relating to their disabilities as well as their ages, gender and nationality. Information about the staff participants is also provided.

Chapter 6 – Conversation Analysis and Ethnomethodology

This chapter describes the key principles underlying Conversation Analysis and the main analytical approach used within this research. In this chapter, literature which discusses and/or uses CA is drawn upon and discussed. Issues which were considered when deciding how to incorporate both ethnographic and CA principles are discussed, and the balance settled upon is outlined.

Chapter 7 – Ethnography

Ethnographic considerations are summarised, addressing how I, as a researcher, influenced what was researched, how it was researched and how the findings are presented. Vulnerability, Relationships, Resistance and Mealtime Interactions are the main themes of this research. How these themes emerged during the research process and how they relate to one another are outlined. Finally, a number of potential research topics which emerged but which were outside the scope of this thesis are listed in the hope that they may serve as a starting point for other researchers.

Chapter 8 – Vulnerability

People with severe-profound intellectual disabilities are considered as 'vulnerable' (Social Care Institute for Excellence, 2015). This conceptual chapter considers how it can be potentially limiting and/or damaging to view people with severe-profound intellectual disabilities as *only* vulnerable. Related literature, comments provided by the Social Care Research Ethics Committee and examples from the data are discussed.

Chapter 9 – Relationships

A case study of a close interpersonal relationship between Jenny, a service user with severe intellectual disabilities, and her keyworker, Luke, is presented in this chapter. A mixed method approach was used, partial interval recordings and interviews were completed, and both quantitative and qualitative data are presented. Then, interactions involving Jenny and various members of staff in similar situations are examined using Conversation Analysis, allowing for the qualities that appear to be special to Jenny and Luke's interactions to be identified and discussed.

Chapter 10 – Resistance

This chapter examines interactions where the participants with severe intellectual disabilities appear to be resisting the activity being proposed by the member of staff in the interaction. Through use of Conversation Analysis various strategies used by people

with severe intellectual disabilities are identified and suggestions for practice are provided.

Chapter 11 – Mealtimes

A close examination of the sequential organisation of mealtime interactions involving the participants with severe intellectual disabilities and care staff is presented in this chapter. Particular attention is paid to how service users and care staff co-ordinate their actions to co-achieve the person with severe intellectual disabilities eating a mouthful of food.

Chapter 12 – Concluding Comments

The concluding chapter of this thesis briefly lists some of the most important findings from each chapter and highlights those which were applicable across different themes. Practical implications and applications of findings are clearly outlined and suggestions for future research are suggested.

2. Introduction and Overview of the Literature

Communication is fundamental to so much of life. Today I have communicated that I wanted a cup of tea and a sandwich and thanked the person providing it. I have phoned family to ensure they were safe after a long journey. I received and sent emails, typed words into search engines resulting in meaningful website suggestions and, of course, I typed some of this very document. I had a back and forth text message conversation with friends, including planning when it would be possible to meet. I also did a silly dance in my kitchen and laughed with my partner. These everyday things such as eating, working or studying, sustaining relationships, and being playful with others are important.

However, I also have the ability to understand and communicate other potentially 'bigger life issues'. For example, I can seek medical help when I am in pain. I can tell people when I do not appreciate how they are treating me. I can leave situations I do not like. I can report, and potentially resist, abusive and/or criminal behaviour. I can tell or demonstrate to people that I care about them, and understand when others tell, or show, me that their feelings are mutual. These varied functions of both verbal and non-verbal communication, expressive and receptive, direct or mediated through technology, are so often taken for granted. Take a moment and begin to imagine a "world without words" (Goode, 1994), or a world without a "shared language" (Caldwell; 2005, 2006, 2008)[1]; without the abilities to express and understand that are so easily assumed. It can be difficult to even imagine such a world, but it is a reality for many. Some people who experience such a world have severe-profound intellectual disabilities. It is their worlds which I have tried to enter and learn, observe and understand.

2.1 Definitions of Intellectual Disability

As outlined in *The Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5; American Psychatric Association, APA, 2013) for a person to be considered to have intellectual disabilities they have to have experienced an early onset of impairments relating to intellectual and adaptive functioning. These difficulties will

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[1] These terms are coined by the authors and referred to throughout their work. For example, Goode's book is titled "A world without words".

have been present since the "developmental period" which the American Association of Intellectual Disabilities operationalises as under 18 years old, although many people with intellectual disabilities experience deficits in reasoning, planning, abstract thinking and learning. Adaptive functioning refers to how well a person handles common demands in life and how independent they are, compared to others of a similar age and background. Some examples of impairments with adaptive functioning include problems with communication, empathy, making and retaining friendships, personal care, job responsibilities and organising school and work tasks (APA, 2013). A person's IQ also features, and those with an IQ of 70 or below are considered to have an intellectual disability. However, recently, adaptive behaviours have been considered more important than IQ when diagnosing intellectual disabilities (APA, 2013). It should also be noted that there are other diagnostic schemes, such as the International Classification of Diseases which is awaiting its 11th edition and the scheme recommended by the British Psychological Society (BPS). Whilst these publications vary slightly, there is a general consensus about the diagnostic criteria for intellectual disability (World Health Organisation, WHO, 1992; BPS, 2015)

Intellectual disability is the currently preferred term for this disability, but it has, and is, referred to by a number of other different terms. Current terms used to describe the same disorder include intellectual developmental disorder (WHO, 1992), learning difficulty and learning disability (British Institute of Learning Disabilities, BILD, 2015). While some of these terms are still popular in the UK, for the sake of trying to ensure all stakeholders are using a consistent term for the disability (Schalock, Luckasson & Shogren; Bellamy et al., 2010) I have favoured the term intellectual disability as it appears to be the term most commonly used internationally. Other terms which have been previously used to refer to what is now known as intellectual disability (but are now not considered to convey the condition respectfully) include mental retardation, mental handicap, mental disability, mental deficiency and mental subnormality (Bellamy et al., 2010).

People with intellectual disabilities experience impairments in three domains: conceptual, social, and practical. Severity of intellectual disability, and its related impairments, vary. In the DSM-5, there are four levels of severity: mild, moderate, severe and profound, though Tassé (2013) questions the usefulness of the distinction between

severe and profound intellectual disabilities. A potential example which supports Tassé's point is outlined towards the end of the section below.

2.1.1 Definitions of severe-profound intellectual disabilities. Approximately 350,000 people in the UK have a severe intellectual disability (NHS, 2018). Such people have limited language skills with both expressive and receptive skills being affected.   As Fuller, Healey, Bradley & Hall note (2004), people with severe-profound intellectual disabilities usually have few or no formal language skills, may not be able to produce or understand speech because of their developmental level and, as they communicate in such idiosyncratic ways, carers may have difficulty recognising and interpreting communication. In addition to language difficulties, such people are likely to experience additional health needs, such as epilepsy, sensory and physical impairments (van Splunder, Stilma, Bernsen & Evenhuis, 2004; Meuwese-Jongejeugd, 2006; Mencap, 2011) which are likely to cause further barriers to communication (Forster & Iacono, 2008). As Ineson (2015) acknowledges, people with severe intellectual disabilities are likely to need high levels of support with most aspects of daily living, and this high level of dependency is likely to exist throughout the person's life (Tadema & Vlascamp, 2009). As Forster and Iacono (2008) and Mattie and Kozen (2007) acknowledge these additional health problems and the medication that is taken to alleviate their symptoms can affect mood, alertness and attention.

Some people with severe intellectual disabilities engage in behaviours that others consider challenging, including aggression and self-harming behaviours (Sigafoos, 2000; Duncan, Matson, Bamburg, Cherry, & Buckley, 1999; Matson, Cooper, Malone & Moskow, 2008; Porter, Ouvery, Morgan & Downs, 2001). These behaviours are often understood to have a communicative function (Bradshaw, 2015).

The DSM-5 (APA, 2013) suggest as follows: Those who have severe intellectual disabilities have limited conceptual skills and generally little understanding of written language, numbers, quantity, time and money, and need support problem solving. Spoken language impairments impact upon the social domain. Many people with severe intellectual disabilities use single words or phrases which may be supplemented through use of augmentative and alternative communication methods. Language is mainly used for social interaction and people with severe intellectual disabilities are thought to understand some simple speech and gestures. In terms of the practical domain, people

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with severe intellectual disabilities need support for all activities of daily living including meals, dressing, bathing and require supervision at all times.

Previous versions of the DSM have used IQ scores to categorise the severity of intellectual disability. This was difficult to measure and is now considered unreliable (Tassé, 2013). More recently the DSM-5 provides specifiers to help determine the severity of a person's intellectual disability based upon adaptive behaviours (pp 34 – 36). This has been perceived as a positive move forward.

However, the differences between severe and profound intellectual disabilities may not always be clear. For example, the DSM-5 states that for those with severe intellectual disabilities, "speech may be single words or phrases and may be supplemented through augmentative means" (p.36, APA, 2013). For people with profound intellectual disabilities the DSM-5 states that they have "very limited understanding of symbolic communication, in speech or gesture. He or she may understand simple instructions or gestures. The individual expresses his or her desires mainly through non-verbal, non-symbolic communication"(p.36, APA, 2013). However, most of the participants with intellectual disabilities in this study, despite being considered by health professionals to have severe intellectual disabilities, had very limited understanding of symbolic communication and mainly used non-verbal, non-symbolic communication. Additionally, in the DSM-5, relationships with family and others are identified as a source of pleasure and help for people with severe and profound intellectual disabilities. This is a large assumption and may not always be the case. A further example, which I identified in an earlier publication (Nicholson, 2017), is that people with severe intellectual disabilities are described as unable to "make responsible decisions regarding well-being of self or others" (p.36, APA, 2013). This strong statement is challenged by the findings of this thesis.

2.2 Defining Interaction and Communication

Goffman (1959) defines social interaction as the way people act, and react, to each other. It is the changing sequence of social actions between people (or groups) who modify their behaviours due to the actions of the person with whom they are interacting. Social interactions are the basis of social relations which in turn are the basis of all social

structure. Interacting with others enables people to relate to one another, and design rules, institutions and systems within which their daily existence is rooted.

This definition of social interaction highlights how important it is to examine interactions involving people with severe intellectual disabilities. It underlines how fundamental interactions are to understanding other people and life within institutions. However, this definition may also present its own difficulties. For example, people with intellectual disabilities who are not intentional communicators may not modify their behaviours for others but may still express emotions or react to behaviours of others, even if their own behaviour is not designed for a recipient.

There is an overlap between the definitions of communication and social interaction. As Hogg and Vaughan (2008) acknowledge "communication is the essence of social interaction" (p.564). As Manusov (2011) outlines, the study of social interaction involves the examination of the communication between people in real-life contexts. Hogg and Vaughan (2008) suggest that for communication to occur there must be a sender, a receiver, a message and a channel of communication. They acknowledge that this is a simplistic model and that senders are also receivers at the same time and vice versa. They also note that multiple messages can be sent at any one time. However, even this understanding does not necessarily capture the complex nature of communication. For example communication attempts made by those with severe intellectual disabilities may go unnoticed or be misinterpreted by the other person. Likewise, people with severe intellectual disabilities may have cognitive impairments which are likely to impact on their understanding of the behaviours of the other. Appropriate expressive communication may also be difficult for both parties.

A "common-sense knowledge" (Garfinkel, 1967) understanding of the terms 'interaction' and 'communication' often involve language and particularly use of speech. Language is considered by many philosophers and linguists as a function that separates humans from non-humans (e.g.Sacks, 1989). However, such opinion is regularly challenged by intellectual disability researchers (Hughes et al., 2011; Goode, 1994), who acknowledge other aspects of what it means to be human. There are also different definitions of language and communication. Communication can take many forms. Language is a formal communication system, and speech is an example of formal symbolic communication where meaning is attached to symbols, in this case words. Sign

language and use of picture boards would also be considered symbolic. Non-symbolic communication methods include facial expressions such as smiling, gestures such as pointing, and other forms of communicating such as using the body, or "bodily expressivity" (Goode, 1994, p.99).

Goode (1994) and Caldwell (e.g. 2006) make arguments that support the view that our current notion of communication is narrow, and does not sufficiently cover the various ways in which it may occur. This means that certain behaviours exhibited by people with severe intellectual disabilities may have communicative functions that are not readily available for us to understand. For this reason, in this thesis, the term 'communication' is used in a broad sense.   All behaviours have been considered to have the potential to be communicative but are not assumed to be designed as such. In addition, I do not try to establish which behaviours are intentional and which are not. As discussed in this thesis, even unintentional behaviours provide information for recipients to respond to and have the potential to shape interactions and therefore carry a message, and have meaning.

2.3 Interactions Involving People with Severe-Profound Intellectual Disabilities

As outlined by Mencap (2008), many people with severe intellectual disabilities do not communicate using formal methods such as speech, signs or symbols. This does not mean that they cannot communicate, but may do so using alternative methods, some of which may be idiosyncratic (Green & Reid, 1996; Carter & Iacono, 2002; Snell, 2002). There also tends to be a reliance on facial expressions, vocalisations, body position and movements to communicate (Purcell, Morris & McConkey, 1999). These behaviours are considered as early communicative behaviours which are often used by infants to convey meaning (Coupe O'Kane & Goldbart, 1998).   Research has also demonstrated that people with severe intellectual disabilities vary in their levels of alertness and general activity and that these levels can change quickly within short periods of time (Mattie & Kozen, 2007). This can affect interaction with others.

The expressive communication of people with severe intellectual disabilities, and the interpretation of it, can be ambiguous (Porter et al., 2001). General l,they have limited speech, with only a few, if any words, and the necessary reliance on non-verbal behaviours can cause difficulties. For example, it may not always be easy to understand

whether a particular behaviour indicates a 'response', a preference, playfulness or resistance. People with severe intellectual disabilities will also have impaired receptive communication and their understanding of language, social conventions and general knowledge is limited.

2.4 Overview of Relevant Guidance and Legislation

Since the turn of the 21st century there has been a noticeable increase in the attention that has been paid to the lives of people with intellectual disabilities. In many cases, however, little attention is paid to people with severe-profound intellectual disabilities and issues that may be particularly important to them. There are two major problems with the recent guidance and legislation. First, people with severe-profound intellectual disabilities are likely to experience additional difficulties to those with mild or moderate intellectual disabilities and these are not appropriately addressed. Second, small everyday decisions, situations where people with severe-profound intellectual disabilities may be able to be fully involved and empowered, are neglected in favour of larger life choices (such as where to live and work).

In 2001 a seminal white paper, Valuing People, was published (Department of Health, DoH, 2001). This paper focused upon the rights of people with intellectual disabilities and was the first white paper on the topic in 30 years. It focused on making lives better for people with intellectual disabilities, dealing with matters such as choice and control, health, young people, housing, employment and quality services. The white paper highlighted four key principles for those with intellectual disabilities: rights, independence, choice and inclusion and focused on ending long stay hospitals and modernising council services. However, whilst the philosophies which underpin the document were welcomed, there were significant omissions from the paper. For example, in the only section that gave a subsection to "People with severe and profound disabilities" (pp. 100-101), it acknowledges that there are additional services such people may need including speech and language support and physiotherapy. The limited comment relating to communication acknowledges that interaction may be difficult, that those with severe to profound intellectual disabilities need others' support, and that they should be enabled to exercise control as much as possible. However, the white paper does not provide any insight as to how to achieve this. Where they refer to decision

making abilities in Valuing People (DoH, 2001), the Profound and Multiple Learning Disability (PMLD) Network (2003) notes:

"There seems to be an assumption that everyone can make concrete choices if given the right communication aid. However, the communication needs of children and adults with PMLD are complex. Many children and adults with PMLD have no formal means of communication, such as speech, signs or symbols. They may use a range of non-verbal means such as facial expression and body language to communicate and be highly reliant on others to interpret these and enable them to be involved in choices and decisions. Because of this, they are often excluded." (p.9)

Specific targets were not set for people with severe-profound intellectual disabilities (PMLD Network, 2003) meaning the general targets that were provided were not always obviously applicable to this group. People with severe-profound intellectual disabilities and their families were not identified as priority groups. As a result, concern was expressed that the needs and rights of people with more severe intellectual disabilities were lost in favour of the wider agenda (PMLD Network, 2003).

Similarly, the white paper "Our Health, Our Care, Our Say" (DoH, 2006), which focused on stronger partnerships between social care and NHS care, did not clearly identify the needs of people with severe or profound intellectual disabilities. Although the need for people with intellectual disabilities to have more control over their own care was acknowledged (see p.101-2), the difficulties in making and/or communicating decisions which are experienced by some people with intellectual disabilities were not considered.

However, around the same time, legislation which did focus on supporting and safeguarding people that may have difficulties making decisions was enacted. The Mental Capacity Act (2005) was passed, and additional government guidance followed in 2007. This is discussed in more detail in chapter 4.

Yet, at around the same time, reports were also published outlining how people with intellectual disabilities were not being treated as equal members of society. For example 'Treat Me Right!' (Mencap, 2004) aimed to decrease the health inequalities experienced by people with intellectual disabilities. Some of these problems are due to difficulties communicating and ensuring that information is provided in an accessible format. Mencap suggested solutions and practical action to be taken. However, no

action or acknowledgement of the report was provided by the government. This led to a follow up report, 'Death By Indifference' (Mencap, 2007) which stated that there was still little attention being given to health inequalities experienced by people with intellectual disabilities, including those related to impaired communication skills which meant that any pain or changes to health could not be easily reported.

In 2009, 'Valuing People Now: a new three year strategy for people with learning difficulties' (DoH) was published. This report aimed to convey that people with intellectual disabilities should be seen and treated as people first and should have the same rights and choices as others. Underpinned by the same philosophy as 'Valuing People' (DoH, 2001) it addresses several of the topics that were omitted from the original report. These included special considerations for those who may have particular additional needs, such as people who are offenders, people with autism and people from ethnic minorities. They also paid more attention to "people with more complex needs." Valuing People Now (DoH, 2009) provided clear steps and objectives to help ensure actual change would occur. However, it is not without its limitations. For example, although the importance of both "the big decisions and the everyday choices" are acknowledged in passing (p.21) the majority of the document focuses on decisions about relatively large issues, such as healthcare, housing, education and employment, rather than the smaller choices. These smaller, everyday choices are particularly important to people with severe-profound intellectual disabilities. There are several reasons why this is the case, not least because smaller decisions, such as how much to eat, who to spend time with and whether to engage in activities or not may be decisions that people with severe-profound intellectual disabilities are able to make and express. Larger life decisions such as where to live and how to spend personal budgets may be more difficult to understand and communicate. Additionally, small decisions occur more frequently thus providing more opportunities to include and empower people with severe-profound intellectual disabilities to have some control over their own lives.

There are also inconsistencies within the document. For example, at times getting people with "complex needs" into paid employment is listed as though there would be few associated difficulties, whereas at other points the likely difficulties and barriers to this are acknowledged. To summarise, the white paper Valuing People Now (DoH, 2009) is a move in the right direction. Its increased focus on human rights, independent living,

having control and being included are welcomed. However, there is still a long way to go before these guiding principles will become reality for everyone with intellectual disabilities.

In 2011, 'Involve Me' was published, the result of a 3-year project examining how to involve people with severe-profound intellectual disabilities fully in decision making and consultations (Mencap, 2011). Eight key points were established. They were: 1) Know the person well 2) Take lots of time 3) Do not make assumptions 4) Be responsive to the person 5) Be creative and try out new ideas 6) Learn from what the person 'tells' you 7) Act on what you learn and 8) Help the person recall and share things about their life. This report gives guidance on how to include people with severe-profound intellectual disabilities, rather than assuming this is easily achieved or simply neglecting it.

Winterbourne View – Time To Change (2012), a report on the enquiry relating to the abuse of people with intellectual disabilities within a care home, highlighted the need to give people with learning disabilities and their families a 'right to challenge' decisions. In the same year, the Care Act (2014) was brought in and set out new principles for adult social care. It stressed the principle of individual wellbeing which included people having control over their day to day lives. In 2015, Norman Lamb, Minister of State at the Department of Health at the time, released a statement reviewing the progress made, which acknowledged that not enough was being done to improve the lives of people with particularly complex needs. Again, however, most of the emphasis was placed on where people should live and how budgets should be spent, rather than on the many small decisions that may occur on a day to day basis. Although the need for control within day to day lives was acknowledged, it was not at the forefront of discussions.

In 2015 the government published the paper "No voice unheard, no right ignored" which focused more directly on how people's rights and choices should be enabled and respected. Use of the Mental Capacity Act (2005) is outlined in this document and it addresses the key rights which people with intellectual disabilities should have. However, once again, the focus still remained on "large issues" such as where a person lives and personal budgets.

Although recent policy and guidance has moved forward in trying to include people with intellectual disabilities in their own lives, there is still a long way to go. There are two major shortcomings of the current documentation. First, the focus tends to be on

"big life decisions" and the smaller everyday decisions receive considerably less attention. Second, the difficulties which a person experiences because of their disability are not fully acknowledged (e.g. DoH, 2001). This failure to acknowledge these difficulties is perhaps because the UK government supports a social model of disability (Parkin, Kennedy, Bate, Long, Hubble & Powell, 2018). As discussed elsewhere in this thesis (see chapters 7 and 8) adopting a social model means that biological differences are not given due attention and important factors which can limit a person's capability are ignored (WHO & World Bank, 2011; Shakespeare, 2006). Without acknowledging the difficulties people with disabilities experience, it is not possible to begin to address them. In contrast, the World Health Organisation promotes the biopsychosocial model of health.

2.5 Intervention Research

Much of the research examining interactions involving people with severe intellectual disabilities is aimed at improving interactions and encouraging positive communicative behaviours by interventions. The research on two of the most commonly used interventions/approaches that are aimed to improve interactions involving people with severe intellectual disabilities is outlined below. They are Intensive Interaction (Nind & Hewett, 2001) and Active Support (Mansell & Beadle-Brown, 2012). Summaries of these approaches have been included as I believe that an understanding of these approaches may situate this research in a broader context and inform interpretations of it.

2.5.1 Intensive Interaction. Intensive interaction is an approach which encourages communication and social skills in people with severe-profound intellectual disabilities (Nind & Hewett, 2001; 2012). The approach acknowledges that people with profound learning difficulties are functioning at the very early stages of development and need to acquire the most simple communication and social skills, such as sharing a space with another person (Kellett, 2005). It promotes the use of very limited speech and instead encourages the non-disabled person to try to consider how the person they are interacting with may think and communicate and "learn their language" (p.98, Caldwell, 2006) and encourages using non-verbal behaviours. Intensive interaction is based on the ideas of Gary Ebinhaus, who suggested an approach based upon mother-infant

interactions and the use of early communication methods (British Institute of Learning Disabilities, 2004).

Nind and Hewett (2012) outline 'fundamentals of communication' to include sharing space, sharing attention with another person, turn taking, using and understanding eye contact, facial expressions, physical contact and other forms of non-verbal communication, including any idiosyncratic behaviours. Many of the principles of Intensive Interaction interventions are similar to other naturalistic interventions and often may reflect best practice (Drysdale, 2011).   Staff or family members may spontaneously use some or all of the principles inherent to this approach (Firth, Elford, Leeming & Crabbe, 2008).

Nind and Hewett (2001) note that people who are verbal often engage in activities that appear to be inherently satisfying. This may include joking, singing, formal and informal games and so on (Finlay, Antaki, Walton & Stribling, 2008). However, as Finlay et al., (2008) and Nind and Hewett (2001) note, when one member of the party has limited or no formal language, these activities need to be tailored to suit the abilities and needs of that person. In providing Intensive Interaction sessions and engaging in playful interactions, the development of various social behaviours such as eye contact, joint attention and turn taking can be encouraged. Intensive Interactions not only have the potential to help develop skills that can be generalised and transferred to other settings (Drysdale, 2011), they can also be enjoyed at the time, intrinsically improving the quality of life of those engaging in them (Kellett, 2005).

There are a number of studies demonstrating the use of Intensive Interactions that report increases in social and communicative behaviours post interventions (e.g. Anderson, 2006; Barber, 2008). Improvements can be seen in increased frequencies of various behaviours, including touch (Barber, 2008; Elgie & Maguire, 2001), eye contact, eye gaze and shared attention and/or joint attention (Barber, 2008; Lovell, Jones & Ephraim, 1996; Kellett, 2003; 2004; 2005) and vocalisations (Elgie & Maguire, 2001; Lovell, Jones & Ephraim, 1998). Anderson (2006) measured the number of turns taken by students with severe intellectual disabilities and also found an increase post intervention. While the empirical studies available tend to support the use of Intensive Interactions, many of the studies are case studies involving only one person with severe-profound intellectual disabilities (e.g. Nind, 1999; Lovell et al., 1998; Elgie & Maguire, 2001; Jones &

Williams, 1998; Kellett 2003; 2004; 2005) or small sample sizes (e.g. Anderson, 2006; Barber, 2008; Leaning & Watson, 2006; Nind, 1996). This is not surprising considering the nature of the research, but should be acknowledged as a limitation. Also, much of this research relies on counting the number of times behaviours occur and this can only provide a partial idea of what the interaction actually looks like.

There are many anecdotal accounts detailing the successful use of intensive interaction (e.g. Caldwell, 2005, 2006, 2008; Nind & Hewett, 2001). Unlike the quantitative studies, these may provide a better idea about the unfolding of the interactions being discussed. However, anecdotal accounts lack the empirical value of systematic studies.

2.5.2 Active Support. Active support is an approach which aims to involve people with intellectual disabilities more in their own lives (Mansell & Beadle-Brown, 2012) and has been demonstrated to be effective with people with severe intellectual disabilities (Stancliffe, Harman, Toogood & McVilly, 2007).   "Active support changes the style of support from 'caring for' to 'working with'. It promotes independence and supports people to take an active part in their own lives. The support given to the person is also active. Active Support enables people with learning disabilities to live ordinary lives."(p.1, British Institue of Learning Disabilities, BILD, 2016).

The idea is to take opportunities where people may not always have been engaged and successfully turn them into interactions where the person with intellectual disabilities is actively engaged through appropriate use of support. An example could involve preparing fruit by providing hand over hand support. An emphasis is placed on providing the right amount of support, not too much and not too little (BILD, 2016).

Jones et al. (2001) demonstrated that training staff in active support increased service user involvement in general and domestic activities. This was further supported when Mansell et al.'s study (2002) found that there were significant changes in engagement in meaningful activities and adaptive behaviour of people with severe intellectual disabilities, where a comparison group did not show any changes. More recent research has also supported the use of active support. For example, observations of 110 people with severe-profound intellectual disabilities alongside use of staff questionnaires found that consistent use of active support was the best predictor of involvement in interactions and was thought to be related to quality support (Beadle-

Brown, Whelton, Richardson, Beecham, Baumket and Bradshaw, 2015). Active support tends to focus upon gross engagement in tasks. For example, Mansell et al., (2002) simply measured engagement on a 4 point scale, ranging from not engaged at all, to engaged over 75% of the time. This gives no indication of the type of engagement or any more specific aspects of the interaction.

2.6 Overview of Research into the Communication and Interactions Involving People with Severe Intellectual Disabilities

There are a number of approaches to examining interactions involving people with severe intellectual disabilities. Hostyn, Petry, Lambrechts and Maes (2011) acknowledged that "interactions are mostly evaluated by investigating strategies or knowledge of the interaction partner (e.g. Dobson et al., 2002; Healy & Noonan Walsh, 2007) or individual communicative utterances by the person with profound and multiple disabilities (e.g. Olsson, 2005) but less by evaluating both partners' behaviours and emotions in relation to each other" (pp.407-408). Below, there follows a brief exposition of the research across these approaches. Belva, Matson, Sipes and Bamburg 's (2012) study obtained information from care staff relating to 204 people with severe and profound intellectual disabilities. They discovered significant differences between the receptive, expressive and written skills of the participants and concluded that adults with profound intellectual disabilities are more able to understand and respond to the communication of others rather than initiate their own interactions. However, this is not to suggest that people with severe-profound intellectual disabilities do not have expressive language skills. Cascella (2005) exemplified this in a study which examined 10 participants' communicative abilities by administering questionnaires to care staff informants. All participants with severe-profound intellectual disabilities were considered to have expressive communication. Nine out of ten of them were considered to communicate intentionally, but it was noted that most were not using symbolic communication methods. All shared certain non-symbolic communication methods as every participant reached for objects and used facial gestures.

Bradshaw (2001) also found that facial expressions and gestures were commonly used, often alongside eye-contact (see also Cascella, 2005). She also comments upon the ambiguous nature of these communicative methods. Cascella and McNamara (2005)

identified communication strategies used by an 11 year old girl with severe intellectual disabilities. They included vocalisations and sounds, words, modified sign language, leading gestures (such as pulling someone), pushing objects, pointing, reaching and showing gestures. She also used eye gaze, head movements, body positioning, facial expressions and holding or pointing to objects.

A technique used in interactions involving people with severe intellectual disabilities is the use of objects of reference. Objects of reference are objects that have special meanings attached to them. They are considered useful for communicating with people who may lack symbolic communication skills necessary for speech and sign language, and are regularly listed as a strategy which people with severe-profound intellectual disabilities respond to (Mencap, 2008). Jones, Pring and Grove (2002) found significant differences between different types of objects of reference. Indices, being objects that are actually used in an activity, such as a paintbrush to represent an art session, were considered more useful in encouraging the use of objects than both icons, such as a photograph of a paintbrush, and symbols, such as a printed letter "A". They measured this in a study involving 13 adults with profound intellectual disabilities over a 20 week period. They made assessments based upon the cues that were provided by staff and service user responses. The idea of a universal system was furthered by Trief, Bruce, Cascella and Ivy (2009). They examined the responses of children with intellectual disabilities to various objects of reference but suggest that use of objects may be a way forward for all working at a pre-symbolic communicative level. Jones et al. (2002) and Trief et al., (2009) also emphasise the importance of indices.

Because of the communication difficulties experienced by people with severe intellectual disabilities, family and support staff are essential in helping them express their choices and preferences (Grove, Bunning, Porter & Olsson, 1999). This makes the communication strategies and techniques used by family members, care staff and others particularly important. For this reason, much of the research conducted has relied upon information provided by them.

Interviews with staff have identified key elements necessary for positive interactions involving people with severe intellectual disabilities. These include knowing the person well (Forster & Iacono, 2008; Martin, O'Conner-Fenelon & Lyons, 2010) and the number of years experience the member of care staff has working with people with

severe-profound intellectual disabilities (Forster & Iacono, 2008; Martin et al., 2010). Suitably adapting communicative style is also considered vital (Healy and Noonan Walsh, 2007; Forster & Iacono, 2008). In their interviews with communication partners, Johnson, Douglas, Bigby and Iacono (2012a) found that interviewees reported routines and comedy, physical contact and presence as key features of good interaction. They also appreciated the importance of interacting for interaction's sake. An emotional bond is also considered essential (Forster & Iacono, 2008; Schuengel, Kef, Damen & Worm, 2010; Johnson, Douglas, Bigby and Iacono, 2012b) However, policy can encourage clear boundaries between professional and social relationships and discourage behaviours which aid attachment, such as physical touch (Forster & Iacono, 2008; Schuengel et al., 2010).

Even when policy supports certain staff behaviours, staff may be unaware of the advantages and/or the appropriateness of certain behaviours. For example, Dobson, Upadhyaya, Conyers and Raghavan (2002) reviewed the literature which focused on the use of touch. They reviewed literature that discussed and/or examined the developmental role of touch, its potential influence on interactions and its communicative functions, including both theoretical papers and empirical studies in their review. Their results suggested a need to help develop an awareness about the different functions of touch in interactions involving people with severe intellectual disabilities. They emphasise that touch should not only relate to providing basic care but should also be used in a social way. Hewett (2007) also highlights the importance of touch in interactions where communication skills are limited.

Staff members may experience difficulty in articulating their communication methods and cannot always clearly identify the successful strategies they use to promote communication (Forster & Iacono, 2008; Healy & Noonan Walsh, 2007). Similarly, there is sometimes a disconnect between the behaviours which staff members report using and those they actually use (e.g. Healy and Noonan Walsh, 2007; Foreman, Arthur-Kelly & Pascoe, 2007). In particular, staff overestimate their use of non-verbal behaviours and underestimate the use of talk (Bradshaw, 2001; Healy & Noonan Walsh, 2007; McConkey, Morris & Purcell, 1999). This research suggests that, even when people are aware of how to support those with intellectual disabilities, they may find it difficult to adjust their communication methods accordingly.

Many acknowledge that challenging behaviours have communicative functions for the person exhibiting them (Cornish & Bramble, 2002; Duncan, Matson, Bamburg, Cherry, & Buckley, 1999; Matson, et al., 2008; Porter, et al., 2001). Using a questionnaire, Lambrechts, Kuppen and Maes (2009) examined the way staff deal with the challenging behaviour of people with severe or profound intellectual disabilities. They found that staff often reacted in a negative way to extreme behaviour.   There is an increasing emphasis on viewing challenging behaviour exhibited by people with severe intellectual disabilities as potentially communicative (e.g. Bradshaw, 2015).

Kamstra, Putten, Maes and Vlaskamp (2018) identified that in their observational study which involved a coding scheme, adults with severe-profound intellectual disabilities were regularly physically positioned by care staff so that it would have been impossible for them to initiate interactions with their peers. For example, for over 60% of their sample, it was not possible for the participant to look towards or touch a peer to able be to initiate an interaction. A similar finding has been found in research involving children with profound intellectual disabilities (Nijs, Penne, Vlaskamp & Maes, 2016). This demonstrates the important role of others in enabling interactions involving people with severe-profound intellectual disabilities. It also highlights the importance of positioning and mobility for initiating interactions and offers a potential partial explanation why it is particularly difficult for people with severe-profound intellectual disabilities to initiate interactions.

Whilst important information can be derived from completing research with family members and care staff, the research shows that it should not be the only technique used to understand the general nature of interactions or when examining communication methods used by both people with severe intellectual disabilities and care staff.

Early research by Clegg, Standen and Cromby (1991b) involved 20 adults with severe-profound intellectual disabilities and care staff. Interactions were videoed and then coded. The findings demonstrated that interactions involved turn-taking and both staff and service user being responsive to each other. This demonstrates the appropriateness of using an interactional approach. However, when Bunning, Smith, Kennedy and Greenham (2013) used a coding scheme based upon functional linguistics to analyse interactions between students with severe-profound intellectual disabilities and

teaching staff, the results demonstrated that teachers dominated the interaction and took significantly more turns than students. Teachers also tended to initiate the interactions and 'follow-up' moves where students provided responses. Teachers used speech, touch, singing and objects to communicate. Students used gestures and vocalisations Bunning et al. (2013), found that initiations made by the students with severe-profound intellectual disabilities, and opportunities for such initiations, were limited.

Hostyn and Maes' literature review (2009) identified four elements key to interaction involving people with profound intellectual disabilities: sensitive responsiveness, joint-attention, co-regulation and an emotional component. As Forster and Iacono (2014) note, there is a "need to engage in a level of microanalysis to register the presence of these qualities in interaction. Such detailed levels of analysis have been conducted in a very small number of studies (e.g. Olsson, 2004; Hostyn et al. 2010)" (p.1106). Whilst my research does not explicitly examine these elements, it does use CA (see below) to provide a microanalysis of interactions involving people with severe intellectual disabilities in an effort to identify those elements of interaction which are, and those which are not, conducive to successful interaction.

2.6.1 Conversation analysis research into interactions involving people with intellectual disabilities. This sub-section discusses research using conversation analysis. Conversation analysis is an analytic technique which allows for the interactional behaviours of all the people involved in an interaction to be examined in relation to one another. This includes non-verbal behaviours. Details of the method are outlined in chapter 6 (Conversation Analysis and Ethnomethodology). Conversation analysts have tried to address the fact that, as Hostyn et al., (2011) and Forester and Iacono (2014) noted, there is limited work that is concerned with the microanalysis of interactions between support staff and people with severe intellectual disabilities. While there are only a few conversation analytic studies involving people with severe-profound intellectual disabilities, there is a body of research which involves people with mild and moderate intellectual disability and so that has been included in this brief summary. Further findings relating to conversation analysis research are discussed and drawn upon in chapter 6, and in the analytical chapters 9, 10 and 11.

Previous CA research involving people with intellectual disabilities has provided examples of how staff propose activities (Antaki, Walton & Finlay, 2007), use various strategies to offer choices (Antaki, Finlay, Walton & Pate, 2008), and pursue questions (Finlay & Antaki, 2012). Other studies detail how staff behave in group meetings involving people with intellectual disabilities (Antaki, Finlay, Sheridan, Jingree & Walton, 2006; Antaki, Finlay & Walton, 2007). Finlay, Antaki & Walton (2007) highlight how nonverbal communication of people with intellectual disabilities can go unnoticed.

Although using conversation analysis allows for the contributions of both staff members and service users with intellectual disabilities to be considered, the research to date focuses more on the behaviour of staff members. Antaki and Wilkinson (2012) acknowledge that this is a pattern when conversation analysis research examines institutional interactions. Focusing on staff behaviours provides the potential to change practice by applying the research findings to give feedback and guidance to staff members (Finlay, 2011; Williams, Ponting, Ford & Rudge, 2009). Aphasia, the language impairment which has received the most attention from conversation analysts, has been studied extensively and the findings of such research have led to the implementation of largely successful interventions (e.g. Saldert, Johansson & Wilkinson, 2015; Wilkinson, 2011; Beeke, Maxim & Wilkinson, 2007; Beeke et al., 2015). If conversation analysis research involving people with intellectual disabilities has a more significant focus upon staff behaviours, it may provide similar insights for staff. However, a downside is that the interactional resources used by people with intellectual disabilities, although considered within the analysis, may not always become a focal point of the research. Although more limited, there are a number of studies that focus on exactly this. For example, Antaki et al., (2017) examine how people with profound intellectual disabilities engage others in interactions and Pilesjö (2014) details how a girl with intellectual disabilities and severe speech and physical impairments co-ordinated her gaze and hand movements as a way to make choices.

Finlay et al., (2008) demonstrate how the ambiguous behaviours exhibited by people with severe intellectual disabilities cause a dilemma for care staff. They discuss two instances where staff members are playing games with service users with severe intellectual disabilities. However, as the games continue, the service user does not provide the target responses relevant to the game. The care staff member then needs to

decide whether to treat the person as legitimately resisting involvement in the game or whether to continue with the game, encouraging further involvement and engagement from the service user.

Finlay, Antaki and Walton (2008), detail how service users with severe intellectual disabilities refuse activities and how care staff respond to that. They offer examples of service users looking, turning and moving away from equipment important for an activity, not taking an "offered hand" and using individualised utterances as means of refusal. They also outline how staff can respond using a no-blame approach, framing the refusal as unproblematic and reframing the activity as joint, something that needs to be co-achieved between the service user and staff member.   However, not all staff members used this approach. Some were not respectful of refusals and treated them as unacceptable. These staff were more directive and challenging in their speech.

Antaki, Crompton, Walton and Finlay (2017) outline how people with profound intellectual disabilities engage others in interaction by examining everyday interactions in a residential home.   They uncovered that there were few examples of the service users initiating interactions and that attempts to do so were often problematic. When service users changed the trajectory of an activity this was more successful than other approaches to engage staff. Their work supports the idea that care staff members often do not adjust their communication methods appropriately, with many staff members responding verbally and not giving sufficient consideration to their non-verbal behaviours.

2.7 Rationale and Research Questions

It is clear from the literature that there is a need for more research which focuses on the nature of interactions involving people with severe to profound intellectual disabilities. If such interactions are to be understood then a close examination of what actually occurs, valuing all people in the interaction, is necessary. By focusing on a fine-grain analysis of everyday activities, information relating to everyday small choices may be provided, something that so far has received little attention both in the literature and related white papers.

The research questions addressed in this thesis emerged from the literature review and my own observations and analysis. I did not start with pre-set hypotheses. These questions emerged during the research process. They are:

1. What do interactions involving people with severe intellectual disabilities actually look like?

2. What influences interactions?

3. Do close relationships exist between service users and staff members? How do these affect interactions?

4. How do service users resist activities? What affects this?

5. How are supported mealtimes co-achieved?

The development of these research interests is described in chapter 7, Ethnography.

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3. Procedural Methods

In this chapter the research protocol and recruitment process are detailed. Then, data collection and video recording, storage and anonymisation processes are described.

3.1 Research Protocol

The overall aim of my research was to identify and examine interactive behaviours being used by people with severe intellectual disabilities and their communication partners in everyday interactions. Examples of everyday interactions include leisure activities, meal times and various therapy sessions. I set out to record 40 hours of interactions and to conduct semi-structured and informal interviews and make ethnographic field notes to contextualise these interactions. However, before data collection could begin it was necessary to secure research sites and recruit participants. The research protocol is presented in chapter 4, Mental Capacity Act.

3.2 Recruitment Processes

3.2.1. Recruiting research sites and gaining official approvals. Day centres and residential homes in the South of England were contacted by both email and telephone and provided with information about my research. Preliminary meetings were held with management of the services to explain my research clearly and to demonstrate that my research interests and personal values were aligned to those of the centres as suggested by Heath, Hindmarsh and Luff (2010). Originally, I was a volunteer at one of the centres before I approached them about completing research there. Recruitment can be particularly difficult when completing research with vulnerable populations and can be considerably easier when a level of trust is already established.

Once I had identified two potential research sites with managers who were keen to support my research I contacted the relevant local authorities who were responsible for running these centres and embarked upon the research governance framework process applying in each of the local authorities concerned. These frameworks were developed for the registration and approval of health and social care research and such approval is necessary in addition to ethical approval, in this case by the Social Care Research Ethics Committee (REC). Before any participants could be recruited, the

research needed to be approved by the local authorities' research governance panels. After receiving a favourable opinion from both the Social Care REC and the relevant local authority research governance panels I could begin visiting the centres.

3.2.2 Details of the two research sites.

3.2.2.1 Langley. Langley was a local authority day centre for people with intellectual disabilities in an urban area. It catered for approximately 40 people. Unfortunately, the centre was closed shortly after the research was completed and although the participants involved within this study had their funding ringfenced and were allocated similar services in the same borough, this was not necessarily the case for those who had less severe, but still life-affecting, disabilities.

There were two separate groups catered for at the centre. The first consisted of people with mild-moderate intellectual disabilities, whilst the second group consisted generally of 10 service users with the most severe intellectual disabilities. The participants in my research belonged to this second group. There were approximately 30 members of staff at the centre, of whom approximately 15 worked with the group with severe intellectual disabilities. The centre was open Monday – Friday, 9am – 3.30pm. Funding was only available for people who were not in residential care, meaning all of the participants from Langley were living within their family home.

The centre worked to a timetable providing different activities each day. These activities included physiotherapy, music, gardening, art, sensory sessions, pampering sessions and interactive story telling. There were also groups who regularly made visits outside the centre for particular activities. These included visiting a local museum, eating out and going to the local hospital swimming pool for hydrotherapy sessions run by care staff.

3.2.2.2 Daisy Way. Daisy Way is a local authority run residential centre for up to seven adults with severe-profound intellectual disabilities. It was also in an urban area. At Daisy Way, care was provided 24 hours a day. There were approximately 22 members of staff, although many of them were not permanent or full time. Most of the residents also attended a day centre for a few days a week, though managers at the centre were concerned that the ability to attend day centres might soon be ended by the local authority. Apart from the residents' bedrooms, there were three other rooms where

residents spent time. These included a living room, a sensory/music room and a kitchen with a dining table. At Daisy Way the residents regularly watched television and listened to the radio. I helped introduce regular Intensive Interaction sessions (see chapter 2 for an overview of II) as a volunteer. Residents spent time in the garden and there were music therapy sessions and massages. There were also regular coffee morning and birthday parties. Kathleen, the manager of the service, had worked in the centre for over 15 years. Unfortunately, by the end of this research project, she had resigned to care for family members.

3.2.3. Familiarisation period at the centres There was a familiarisation period of approximately four weeks built into the research protocol. During this period, I spent time visiting the centres helping with activities. Examples include helping at mealtimes, going on community outings and collecting ingredients for sessions from local markets. I also joined in music sessions and interactive stories and helped service users in and out of coats and other outdoor clothing.   Generally, I tried to act as another member of staff would within an appropriate remit. I did not, for example, provide personal care. Although I briefed staff informally about my research, I did not try to recruit staff or service users during this period. The familiarisation period was important for a number of reasons. As Heath et al. (2010) note, issues relating to gaining access and agreement to conduct video-based qualitative research is about both "getting in", gaining physical access to an organisation, and "getting on", gaining the trust and participation of the people within the organisation. Without due consideration, either can cause problems with recruitment and data collection. This time allowed me to liaise with senior management about how the centres were run, to observe the day-to-day practices of the centre and to collate any documents regarding the service's safeguarding and other procedures relating to general safety, such as fire policies. It also allowed me to learn and build trust and relationships with the staff and service users. It meant I had time to get to know everyone at the organisations, including those who may not have been suitable for this research, allowing me to be sensitive to the needs of everyone I would be spending time around while collecting my data.

3.2.4. Recruiting people with severe intellectual disabilities. It was likely that most, if not all, of the potential participants with severe intellectual disabilities would not

have been able to give informed consent. Although this was not assumed, because of the potential participants' impairing conditions it was a genuine possibility. Because of this, the Mental Capacity Act (2005) and guidance relating to using the Act in research projects were followed (Mental Capacity Act Guidance, 2007; Dobson, 2008). Discussion about the Act, its impact on this research and how recruitment and participation of people with severe-profound intellectual disabilities was carried out in accordance with it appears in chapter 4.

3.2.5 Recruiting staff members. After this familiarisation period, all staff members were approached and invited to participate in the research. As I had been visiting the centres for some time, I had already had several informal conversations with staff members about my forthcoming research before I was actively recruiting. I held short staff meetings, without any management staff present, as an economical way to disseminate the information about this research with an opportunity for open discussion and questions. However, I also ensured that I spoke to each staff member individually, again not in the presence of management, to ensure that they had the opportunity to raise any questions or issues freely without feeling pressurised by employers to participate in the study. Each member of staff was provided with an information sheet (see Appendix A). This information sheet outlined the purpose of the research, what it would involve and stated that jobs would not be affected by non-participation. It explained that there was no requirement to participate and that the data would not be passed onto management for monitoring or assessment purposes. Employees' rights regarding withdrawal, confidentiality and anonymity were also explained. If staff were willing to be included in my research, informed written consent was obtained (see Appendix B).

3.2.6 Recruiting other professionals. Many professionals provide services to people with severe intellectual disabilities on a regular basis. Such professionals may visit the day or residential centres to provide these services, or the service users may visit them elsewhere. Examples of these professionals include, for example, mini bus drivers, art or music therapists, speech and language therapists and student nurses. As regular communication partners with people with severe intellectual disabilities, I was keen to include such professionals in my research. Any professionals who visited the services during my familiarisation period were briefed about the purpose of the research and

where possible, during my recruitment period, I personally provided information sheets, which included the same information regarding the person's rights as described above but were tailored for visiting professionals (see Appendix C). I ensured time was made to discuss the research and answer any questions following which written consent was sought from those who were willing to participate (see Appendix B).

Professionals whom I did not meet during my familiarisation and/or recruitment periods were sent a letter or an email outlining my research (see Appendix D). To protect the privacy of the potential participants I had not yet met, including staff and visiting professionals and family members this correspondence was forwarded by the service manager. Attached was an information sheet clearly explaining relevant information about the research (Appendix A and C). It also explained that there was no obligation to participate and that their jobs and/or relationship with the centre would be unaffected by their decision. I asked those willing to discuss the research further to contact me directly. Written consent was sought from those willing to participate.

3.3 Data Collection

3.3.1 General Data Collection Procedure. Video data were collected by using either one or two Panasonic HC-V110 high definition hand held video cameras. A small table top tripod was also used when appropriate. I chose positions which meant that only consenting individuals were filmed but also tried to position myself appropriately for the activity. For example, I would sit within the group circle during large music sessions, but during 1-1 physiotherapy sessions I would sit on a chair at the side. As I wanted to be able to monitor the cameras, I never left them unattended. There was a short camera familiarisation period so that I had experience managing the camera(s) and the participants had some time to adjust to the presence of the camera without actually being filmed.

A range of activities were recorded. These included physiotherapy sessions, people listening to music together, more formal music sessions, gardening sessions, an eye-gaze technology assessment, mealtimes, art sessions, people relaxing in the living room, hydrotherapy sessions, foot spas and interactive stories. Recordings were also made of sessions where people were mobilised and allowed to move around freely on their scooters or kneepads.

Semi-structured interviews were conducted in a quiet room at the centre. One of the cameras was used to capture the audio record of the interview. Interview schedules (Willig, 2001), consisting of a list of topics to cover were followed. I completed interviews with Luke, a member of care staff to gain more insight into his relationship with Jenny, a service user. More extensive details about the interview process and the interviews themselves are provided in chapter 9.

To ensure it was possible to write up my ethnographic notes immediately after visiting the centres, I would routinely schedule time to do this. When visiting the day centre I would visit a public library afterwards whereas at the residential centre I wrote my notes up either in the kitchen or the sleeping-in room, whichever was empty. I tried to note the position of everyone in the room to help understand anything that occurred off camera but because of the nature of care centres, people's positions often changed. I also recorded anything that struck me as particularly noteworthy, such as strategies that I had not seen before or behaviour that I considered to appear particularly effective. For example, I noted the various sensory choices Simon was offered when he slapped his face, noting he regularly calmed when his hands were in water. Deciding what to note was difficult, particularly at first but it became easier as the themes emerged through data collection.

3.3.2. Turning the camera off and additional consent. It would not be appropriate to film every part of a person's everyday life. To address this, certain scenes were outlined as not suitable for filming. After discussion with the Social Care REC before data collection began it was agreed that toileting, nudity and sensitive scenes relating to a person's disability, such as seizures or hoisting would not be filmed. When participants had seizures mid-scene the camera was turned off. Interestingly, staff from both centres commented on how it would be useful to have filmed footage of managing seizures and/or hoisting in different situations. One poignant example was that when one participant had a seizure during a hydrotherapy session the staff were rather disappointed that it could not be captured on camera so that their expertise in managing the unusual situation quickly and effectively could be shared. It may be appropriate for such situations to be filmed for the purposes of research/staff training. However, I acknowledge that such research would give rise to further ethical considerations and be outside the scope of this project.

In addition to avoiding scenes of a particularly sensitive nature, if there were any signs that the person with intellectual disabilities was not happy being filmed, the camera would have been turned off immediately. I identified which behaviours signalled unhappiness by the use of communication passports which I put together and were informed by care staff and family members. I also used any existing documentation about communication methods by service users. These had sometimes been compiled by speech and language therapists. Unhappiness was considered to be demonstrated by frowning facial expressions, screaming, moving away from people or objects, crying and idiosyncratic self-harming behaviours including slapping their own face and biting their hand. Whilst some of these behaviours were captured *on* camera, there was never any reason to believe this was *because of* the camera. Although no participant exhibited behaviours that led to the belief that they wished the camera to be turned off, the camera was at times turned off because it was felt that the scene had become sensitive. For example, the camera was turned off because of participants self-harming (e.g. biting themselves or head banging), becoming aggressive or extremely upset seemingly because of reasons other than the camera.

Before turning the camera on, everyone present was asked if they were happy to be filmed. All participants were told they were able to ask for the camera to be turned off at any point, for any reason. Staff did sometimes ask for the camera to be turned off and this was always respected. After each session, it was checked that all staff were happy with the video being kept and used in this research. Staff always agreed. These additional consent procedures were put in place to ensure that all participants felt comfortable with all of their involvement in the research and to overcome other potential problems (such as participants avoiding the view of the camera; Heath et al., 2010).

3.4 Video Management, Storage and Anonymisation

In total 40 hours of video data were collected. These videos are stored on Kingston Secure Digital Cards and on two encrypted external hard-drives (My Passport Ultras, 1TB) which are kept in a locked filing cabinet. After attending training on managing a video corpus (Albert, 2014a), each video file was named using the date it was filmed with pseudonym names and a short description of the scene (in the format yyyy-mm-dd- pseudonym-and-pseudonym-short-description). As recommend by Heath et al

(2010) a preliminary review was conducted and consisted of making an excel file with the file name and duration of each video. This labelling system meant that files were easy to organise and to search through.

As explained on the information sheets and consent forms supplied to all participants (see Appendix A-C), when videos were (or are to be) shown outside of my supervisory team they have been (and will be) anonymised. This is achieved by the use of the video editing software, Sony Vegas Pro 12. Adding the effects of a filter and a slight blur anonymises the identity of those being filmed but allows many non-verbal behaviours (such as hand, head and body movements) still to be observed. The pitch of people's voices was also edited for the sake of anonymity. This was achieved either in Sony Vegas Pro 12 or Audacity. In all publications, including this thesis, pseudonyms are used.

4. Mental Capacity Act

Compliance with the Mental Capacity Act (MCA; 2005) was an integral part of this project. This chapter outlines the key features of the Act and how they have been applied specifically to the research presented within this thesis.

4.1 Informed Consent

Because of the vulnerable nature of some of my participants, and the likelihood that some, if not all, of my participants with severe-profound intellectual disabilities would have been unable to give informed consent, ethical considerations were an integral part of my research. Gaining consent which is full, informed and voluntary is a guiding principle of all research (World Medic Association, 2013; Nuremburg Code of Ethical Practice, 1947 cited in Mitscherlich & Mielke, 1949). The importance of seeking appropriate consent is mirrored in the Research Governance Framework for Health and Social Care (2004) and NHS guidance (NHS, 2003). However, some people may lack the mental capacity to be able to provide such consent. This presents a dilemma, as to exclude people who lack the ability to give informed consent from research is also problematic. If certain groups are not the subject of research then the potential knowledge and understanding of those particular groups that could be gained through research is lost (Gelling, 2004). Lai, Elliott and Ouellette-Kuntz (2006) and Iacono and Murray (2003) highlight the challenges of safeguarding vulnerable groups while ensuring that they are not denied the benefits that research can offer. Research that aims to include groups who may not have the capacity to consent must be approved by an "appropriate body" (MCA, 2005 – Section 31).

4.2 Ethical Approval and Professional Training

This research was approved by the Social Care REC and the Research Governance Boards of the local authorities responsible for the research sites. After taking time to learn the application process and system, I published an article which aimed to help other early researchers applying to "appropriate bodies" (Nicholson, 2015).

To acquire additional skills to lead this project, I completed a number of training modules on the MCA (2005), completing mental capacity assessments and safeguarding vulnerable adults.

4.3 Key Principles of the Mental Capacity Act

The MCA (2005) is a statutory framework which was introduced to help empower and protect vulnerable people. The purpose of the Act is not solely to protect people as participants in research projects but to provide protection for people who lack the capacity to consent to actions or processes in their everyday lives. However, it also acknowledges that conducting research with those who may not have the capacity to consent directly needs to be handled carefully. As Dobson (2008) and Calveley (2012) note, the Act enables people who lack the capacity to consent to research to be included and sets out statutory requirements about how to achieve this. In research involving those who lack mental capacity it is vital to be able to demonstrate that participation is in their best interests and does not infringe on their rights and freedoms. The five main principles of the Act, provisions which are concerned with conducting research, and how these they relate to my research, are set out below.

4.3.1 Assume capacity. The MCA (2005) states that everyone should be assumed to have capacity, unless there is reason to believe otherwise. The MCA and the MCA Code of Practice (2005) outline that a person lacking capacity has an impairment or disturbance to the mind or brain that causes their inability to make a particular decision at a particular time. It is suggested that there should be a two-part test of the mental capacity to make decisions. The first questions whether the individual has any cognitive impairment and the second questions whether any such impairment prevents the person from adequately completing any stage of the decision making process. The MCA (2005) breaks this down into four sections: understanding, retaining, using and weighing up information, and communicating the decision. Failure at any stage of the process can inhibit effective decision making.

Whilst it was unlikely that individuals with severe-profound intellectual disabilities would be functioning at a developmental level successfully to understand, retain, use, weigh up and communicate their consent to participate in research, they could not be assumed to lack capacity simply because of their condition. Each potential participant

was assessed individually. An assessment of capacity form (see Appendix E) was completed by a health professional in my presence. I ensured that the health professional understood the purpose of the form and discussed each part of it with them. This is because recent studies have demonstrated that staff lack confidence in completing assessment of capacity forms and there are common misconceptions about the purpose of the forms and the principles of the MCA (Willner, Bailey, Parry & Dymond, 2010).

4.3.2 Give all practical help. Before any person is assumed to lack capacity to make a decision, the MCA (2005) requires that all practical support that may help them make the decision be provided. I ensured that all practical help was given by getting to know the potential participants and their favoured communication styles first. Any avenue that could have enhanced the potential participants' mental capacity to make a decision was explored.   Adaptations to materials included translating the information into Portuguese (the language used within the home of a participant) and Makaton, and presenting the information in picture form and easy-read text.

Those that know the potential participants well, family, friends and health professionals may be able to help communicate the information about the study in the most accessible format. People who know the potential participants well can be used to help deliver, or advise the best way to deliver, information. I utilised this source, presenting the information with keyworkers or service managers who know the potential participants well. I studied, updated and where necessary, developed the potential participants' communication passports or profiles. These are records detailing effective ways to communicate and support the participant, as well as their interests and other important information about them (Mencap, 2013). This ensured that I was aware of the best way to present information relating to the research to each person and had information to help me understand their potential responses.

4.3.3 Respect 'unwise' decisions. The MCA (2005) states that a person should not be treated as if they are incapable of making a decision, just because they are deemed to have made a decision that is deemed to be unwise. This principle of the MCA is probably more relevant for research involving treatment, or research of a more intrusive nature. As my research is observational, this principle is only relevant to respecting everyone's right to object to participating in the research or to withdraw. These are underlying principles of all psychological research, whether involving participants with mental

capacity or not. Participants were regularly monitored for changes in mood or behaviours which may have been related to participating in the research. If participating in the project had appeared to cause any changes in behaviour or mood of a participant, or family or carers were to have raised concerns about a person's continued willingness to participate in the research, the participant would have been excluded. Whilst there was a change in mood of one of the participants, his family and health workers considered this to be a result of declining health, rather than being involved in the research. At a best interests meeting, this was discussed with several people who were involved in his life, including family members, care staff and medical professionals who agreed this was a more general problem for the participant. This participant was not withdrawn from the research. After many assessments and treatment for various health conditions, his mood and behaviours returned to normal.

4.3.4 Best interests. Calveley (2012) used Beauchamp and Childress's (1989) ethical framework to weigh up the potential risks and benefits of participation vs. non participation in her research. This framework outlines the principles of justice, autonomy, beneficence and nonmaleficence. Similarly, the American Psychology Association ethical code of conduct (2017) may be of use to ensure that research is in the best interests of participants. This has five guiding principles: beneficence and nonmaleficence, fidelity and responsibility, integrity, justice and respect for people's rights and dignity. However, both of these ethical frameworks present the problem that some of the principles they use may be in conflict (Calvely, 2012). This means that the decision about which is more important is a subjective one which falls to the researcher. Calvely emphasises that the framework is not a perfect solution, but it can help focus thought on identifying the genuine benefits and risks.

4.3.4.1 The risks. The MCA Code of Practice (2007) stresses the importance of ensuring that the benefits of the research outweigh the burdens of it. My research has the potential to benefit the participants in a number of ways and has limited risks. As set out in the MCA (2005), my research would not be considered unduly invasive as it is an exploratory study of naturalistic everyday interactions. The actions which the participants would carry out in the course of the research would not significantly differ from their everyday lives. Furthermore, in line with the MCA Code of Practice (2007), the risk to the participants is minimal. No harm should be caused by the research, and I would have

stopped if any signs of distress by the participants appeared or were communicated by others to be caused by my actions in the course of the research.

To aid with understanding of how each participant communicated distress (and indeed other emotions) a number of steps were taken. First, before the project started there was a familiarisation period which allowed me to take time to learn about each participant and their communication methods. I also liaised with staff and family members to discuss their communication preferences. I also used, or developed, 'communication passports/profiles'. These helped me identify behaviours that may be communicative (including any signs of distress), and after the project may have provided a more effective way of sharing unique details and preferences of the participants – increasing their quality of care (Cascella & McNamara, 2005).

4.3.4.2 The benefits. The research provided further benefits. It meets two of the required benefits set out in the MCA. First, it provides the possibility of increasing the quality of care both generally for people with profound intellectual disabilities and particularly for those involved in the study. It also decreases the risk of being excluded.

4.3.4.3 Increasing the quality of care. The aim of the study was to capture communications between people with severe-profound intellectual disabilities and others to identify effective communication strategies. This would benefit participants in the study and others with the same or similar conditions. By way of example, the introduction of communication passports/profiles could benefit not only those involved in the study but also, if the institution found them a useful tool, they could be used more widely.

4.3.4.4. Decreasing the risk of being excluded. This research also decreased the risk of people with severe-profound intellectual disabilities being excluded in several ways. Much of the current research on people with intellectual disabilities focuses on people with relatively mild intellectual disabilities, and it does not adequately represent people with more severe disabilities. There is a danger that this group of people will become an invisible section of the population (Finlay et al., 2008), and it could be argued that this has already begun to occur within the literature. Cambridge, Forester and Jones (2003) suggest that the involvement of people with more able verbal skills in research has skewed the sampling of people with intellectual disabilities. My research aimed to begin to address this significant gap in this body of research. To this end, conducting and

publishing the research itself begins to address issues of exclusion in the academic literature.

Furthermore, it is likely that people with severe intellectual disabilities are sometimes excluded from certain activities/interactions because of their limited communication. Close examination of interactions should uncover communication methods used and help to decrease this risk.

4.3.5 Avoid restriction of basic rights and freedoms. The MCA (2005) outlines that any decision or action made on behalf of another person should be the least restrictive of their basic rights and freedoms. My research did not place significant restrictions on the participants as I was simply observing elements of their everyday lives. However, the observation itself, or use of a video camera, may have the potential to cause distress to a participant. Scenes of a sensitive nature, such as hoisting, seizures and nudity were not filmed. Situations where filming could and could not take place were set out to, and approved by, the Social REC. Distress was monitored by myself and asked about at monthly reviews with family members, friends and care professionals. Further rights of the participants were considered and addressed and were in line with the British Psychological Society's Code of Ethics and Conduct (2009).

4.4 Section 31 of the Mental Capacity Act – Requirements for Approval

This section of the MCA provides that research involving those with an impairing condition may only be conducted with the consent of an "approved body". The participants in this research who lacked the mental capacity to consent all had severe intellectual disabilities which would meet the Act's criteria for an impairing condition (MCA Section 31.2 and 31.3). Research of comparable effectiveness could not be completed without their involvement (MCA Section 31.4), and the research aimed to provide all participants with potential benefits without imposing potential burdens (MCA Section 31.5a). However, even if this criterion was deemed not to be met, this research also intended to provide knowledge about care provided to people with similar conditions (MCA Section 31.5b) whilst the risks to the participants, and the invasiveness and interference that participation would cause to their freedom, were negligible (MCA Section 31.6).

After the project was approved by the Social Care REC and the Research Governance Bodies, I followed a research protocol (see Figure 2) and mental capacity assessments were completed. Upon completing mental capacity assessments, it was found that none of the potential participants had mental capacity to consent. At this point it was important to involve consultees.

4.5 Section 32 of the Mental Capacity Act - Use of Consultees

When approved research is conducted involving people who lack that capacity to consent, steps must be taken to identify, for each potential participant, a person who cares for them, without payment, other than in a professional setting, who is happy to be consulted (MCA Section 32.1 & 32.2). An email/letter was sent via the centres to potential consultees (see Appendix F). They were provided with information about the research (see Appendix G). They were asked for advice about whether the potential participant, their relative, should participate in the research and for their opinion about what the potential participant's wishes and feelings about the project would be likely to be if they had capacity in line with MCA Section 32.4 (see Appendix H). All consultees advised that they believed their relative with severe-profound intellectual disabilities would wish to be involved in the research if they had the capacity to consent. Contact was maintained with consultees throughout the research so that they had the opportunity to advise if they believed the participant would be likely to want to withdraw (MCA, Section 32.5). They had the opportunity to raise this during monthly reviews, but none did so.

4.6 Section 33 of the Mental Capacity Act – Additional Safeguards

Section 33 sets out additional safeguards. It states that research should not be conducted if the participant appears to object to it (by resisting or by other means) and that nothing should be completed that is contrary to any advance decision or other type of statement (MCA Section 33.2) None of the participants had made any advanced decisions, though this is perhaps unsurprising given the nature of their disability. I also undertook to discontinue the participation of anyone who showed signs of objecting to

the research and, I made specific efforts to collect available information about how a participant might express their objection. However, this situation did not arise.

Points within this section relate to ethical considerations that are necessary for all research, such as the interests of the person must be assumed to outweigh those of science and society (MCA Section 33.3). It also covers when to withdraw a participant when circumstances change (MCA Section 33.4, 33.5, 33.6). Had circumstances changed I would have notified the REC immediately. To ensure I was constantly reviewing the circumstances, ethnographic field notes were made and monthly reviews, which involved consultees, completed.

4.7 Adapted process for research involving people who lack the capacity to consent

Figure 1 taken from from Dobson (2008) sets out in diagrammatic form the usual process for the conduct of research from start to completion. Figure 2, also taken from Dobson (2008) show the adaptations required where there are particular ethical considerations arising, as in this case, from an inability to give consent.
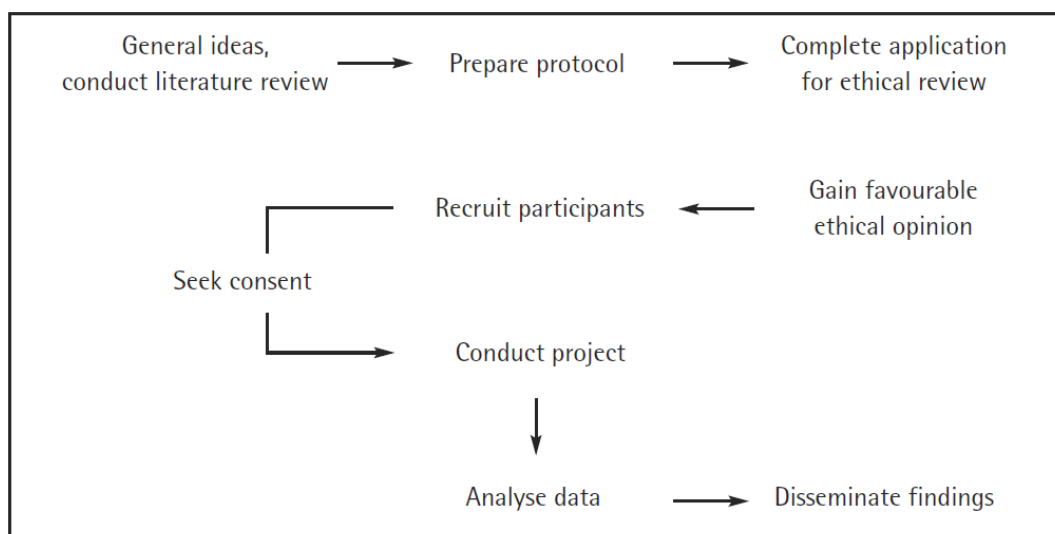
Figure 1 – The typical research protocol (Dobson, 2008).
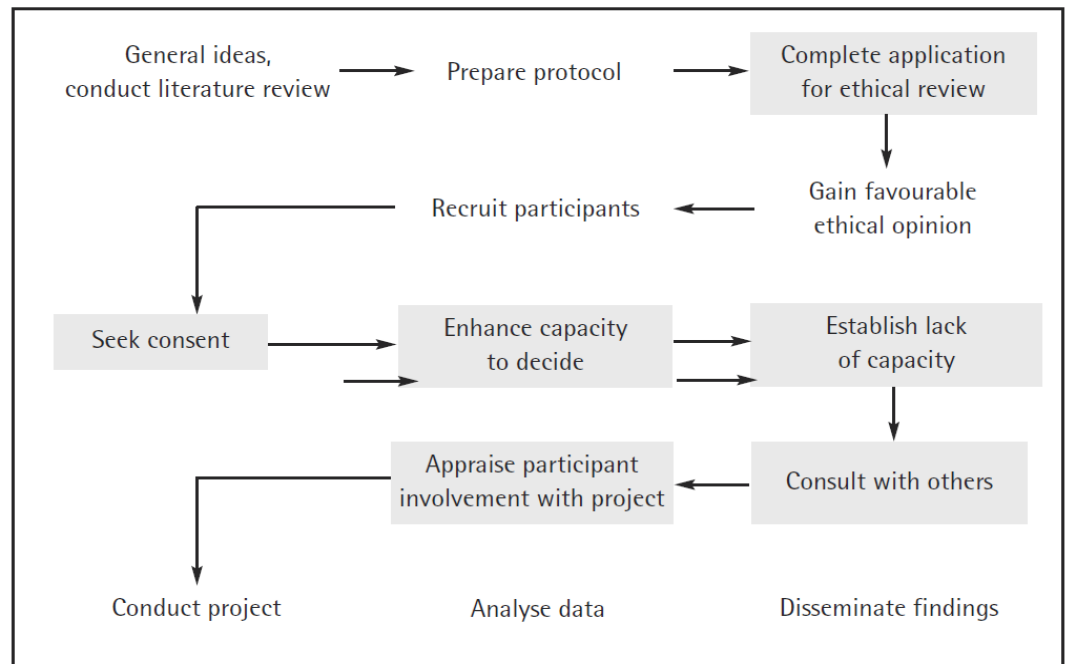
Figure 2 – The adapted research protocol for research involving people who may not have the capacity to consent (Dobson, 2008).

This chapter deals specifically with the ethical considerations arising out of the Mental Capacity Act (2005). Given the vulnerability of participants it was essential to focus particularly on the legislative framework to ensure that their interests were safeguarded. However, the provisions in the Mental Capacity Act (2005) were not the only ethical considerations in this project. Issues such as security, confidentiality and anonymity were also paramount. They are dealt with in chapter 3, Procedural Methods.

5. Participants

This chapter provides details of the participants who were involved in this research.

5.1 Summary

Participants were recruited from two research sites which both cater for people with intellectual disabilities. The first is Langley, a day centre, and the second Daisy Way, a residential centre. For details of these two research sites and how they were recruited please see chapter 3. Five participants with intellectual disabilities were recruited as well as sixteen members of staff employed in the research sites. In addition, one speech and language therapist assistant, a physiotherapist and their assistant, a masseuse and a volunteer on an international project were also recruited.

All five of the participants with intellectual disabilities are classified in their health and social care records as having severe intellectual disabilities. Additional information about their health conditions, mobility and communicative abilities are described below.

Other information was collected from the participants' social care files. These records were completed to a similar level of detail, but they had been completed by different professionals and did not necessarily give exactly the same information. For example, some practitioners noted that a participant suffered from epilepsy, whilst others referred to the specific type of epilepsy suffered. This explains any discrepancies in the specificity of the impairments listed.

5.2 Participants with severe intellectual disabilities at Langley

5.2.1 Simon. Simon is a 32 year old man with Sturge Webber Syndrome, a rare neurological disorder. Sturge Webber Syndrome is marked by port wine stains on the face, which Simon has on his left side. Port wine stains are birthmarks caused by an overabundance of capillaries near the surface of the skin. Blood vessels in the brain may also be affected. As is also typical of Sturge Webber Syndrome, he suffers from tonic clonic seizures; seizures which affect the whole brain. Simon has eczema and psoriasis, both skin conditions which cause dry flaky skin and discomfort. He also has limited vision in his left eye.

Simon does not use speech but can vocalise including by way of grunts, wailing and panting. His understanding of speech is unclear. He reaches out or out-stretches his fingers towards objects, and these actions are interpreted by others as him expressing that he wants the object. Likewise, when he drops objects or pushes away an object this is considered to demonstrate that he does not want it.   Simon's gaze direction is also thought to be indicative of his likes and desires.

He generally uses a wheelchair for mobility. Although Simon can use his wheelchair somewhat independently, his lack of spatial skills often means that is not possible and he is not permitted to move around independently when outdoors. He also has sessions at the centre where he uses a gait trainer, a walking frame which he is strapped to, which, once he is supported into, he can use independently.

Simon often rocks back and forth and engages in scratching and slapping his own face or hitting it with objects. The force with which he completes these activities varies from seemingly satisfying a small itch or lightly self-stimulating to behaviour that would be categorised as self-injurious. Occasionally he bites his hand. This is thought to happen when he is very upset.

Simon lives at home with both parents. He also has several carers who visit him at home.

5.2.2 Jake. Jake is a 31 year old man. His social care records record him as having "brain damage" thought to be due to a lack of oxygen at birth. This could loosely be described as cerebral palsy. Within his notes this is generally referred to as quadriplegic cerebral palsy, a type of neurological disorder which affects all four limbs. He also has epilepsy and non-specific apnoea, which means he could stop breathing at any time.

Jake does not speak or produce any other formalised language but can vocalise. He is able to laugh and scream. He can also display his emotions by crying. His understanding of speech is unclear. He uses a wheelchair or a specially made "scooter" for mobility. His movements towards, or away from, an object or people are considered to demonstrate his preferences. Additionally, when presented with two objects, Jake's eye gaze and/or touching of one of the objects is considered to indicate his choice. He is also considered to communicate via facial expressions and gesture.

Jake lives with his father in an adapted flat which meets his needs and promotes his independence.

5.2.3 Jenny. Jenny is a 35 year old woman. She has cerebral palsy. Her family speak Portuguese at home. She is reported to be able to understand basic words in Portuguese (such as give, here, drink) but her understanding of English is less clear. She is a wheelchair user but is able to move around on her knees. Supported, she can walk a short distance.

She has no speech and does not produce any formalised language. Instead she communicates using facial expressions, vocalisations (such as squealing, laughing and panting), eye-gaze, proximity to people and/or objects, posture and gestures.

5.3 Participants with severe intellectual disabilities at Daisy Way

All the participants recruited through Daisy Way are permanent residents there.

5.3.1 Patrick. Patrick is a 48 year old man. He has cerebral palsy and left sided hemiplegia, meaning his movement is both disrupted and limited on the left side of his body. Patrick uses a wheelchair.

Patrick has a limited verbal repertoire but can produce a few phrases, words and noises. He can say "E I E I O" a line from a children's song about the noises on a farm, "oooh nice" and "aaeh" which is understood to be used by Patrick used to express pleasure. When he claps his hands, it is considered by family and care staff to mean "yes" or as a sign of enjoyment. Patrick can also blow raspberries. Although his movement is disrupted on the left side of his body, he is able to grab, pull and push objects with his other hand. Whilst these actions are considered as meaningful by others, they are also considered a risk to staff because he pulls and grabs staff, and has been known to scratch. He is also considered to communicate using eye-contact, gesture and posture. Patrick is considered by care staff to understand a few phrases, but his general understanding remains unclear.

Patrick loves music and spends much of his time listening, moving and clapping to it. Patrick's mother and sister live locally and visit the centre for special occasions and take Patrick to attend family celebrations. They also organise typical social events in the community, such as having lunch or going shopping, with Patrick.

5.3.2 Thomas. Thomas is a 42 year old man. He is reported to have "chronic axonal degeneration neuropathy" which involves degeneration due to axon death. Thomas also has epilepsy. He has a tremor which means his head regularly shakes, but

this was not considered by the staff necessarily to mean "no" or represent a disaffirmative response as it is not an action over which he has control.

Thomas's verbal and/or cognitive abilities are variable but declining. When able to contribute verbally, he has a very significant delay in producing speech and often responds to talk that has happened much earlier in the interaction, suggesting some understanding but a much slower processing time. Thomas will often look people straight in the eye, regularly accompanied by a large smile. His gaze direction is understood to be meaningful by others.

Thomas's mother visits once a week and is well known within the centre. Thomas also goes to visit other family members on a less regular basis.

Appendix I, summarises the key features and abilities of the participants with severe intellectual disabilities.

5.4 Death of Participants

Originally, five participants with severe intellectual disabilities and one participant with profound intellectual disabilities were recruited for this research project. Sadly, the participant with profound intellectual disabilities died very early into the project. Considering the sensitivity involved in dealing with a participant's death within a research environment and the ethical and moral considerations which accompany it (Kellett, 2005), I decided to remove her footage from the corpus. Another of my potential participants died before he was recruited.

Death is a very real risk when completing research involving people with such complex health needs. These losses for me had a much greater personal impact than they had upon my research. Whilst it is true that, logistically, researchers should consider the delays that a death within a care setting may have upon progressing their research, consideration should also be paid to the potential emotional effects of such a loss both on the researcher and others within their research environment. I remember them both warmly and would like to thank their kind families and care staff who thought it appropriate to both inform me of the losses and invite me to funerals and memorial services. It was my honour to get to know them and their memory remains one of my strongest motivators.

5.5 Care staff at Langley

Twelve staff members were recruited through Langley. Eleven of these were care staff and one a member of management. All but two of the members of staff had at least five years experience working in care. Within the sample there were five females and six males.

5.6 Care staff at Daisy Way

Although during my familiarisation stage at Daisy Way I had interest from several of the members of staff, I was not able to recruit all of those who had originally expressed interest. During my time at Daisy, a manager who had run the service for over fifteen years retired. Her departure, and departures which followed soon after, had a real effect upon the centre. Staff turnover increased and many of my potential participants, who had got to know and trust me both as a volunteer and a researcher, no longer worked at the service. The enthusiasm and trust that had been fostered, appeared at least to be based upon our shared experiences and interests. Shared activities such as coffee mornings, Christmas celebrations, routine Friday afternoons within the centre, funeral attendances, community trips and so on helped build the relationship between me and the "old" workforce and demonstrate my real commitment to improving the lives of the residents and others with similar health and/or communication difficulties. The "old" workforce had an extended opportunity to observe my commitment to both this research and the centre, and particularly to the residents themselves. As I had the full and unreserved support of the management team, potential recruitment originally looked likely. However, asking the newer staff members to participate in research, when they were only just getting to know both myself and the residents, was a bigger ask and my recruitment was less successful than I had originally hoped.

At Daisy Way, four members of care staff were recruited. Three of these had worked there since I first had contact with the centre. These three all had over five years experience working within care. The other staff member was relatively new to care but was clearly very eager to learn. She regularly asked me to direct her to literature and started poignant, intellectual discussions relating to the welfare of the residents and how best to support them. Two of the staff participants were female and the other two male. I also recruited an international volunteer who volunteered full time at the centre.

Recruited visiting staff included a masseuse who visited the centre on a weekly basis to provide massages to some of the residents including Thomas and Patrick, and a speech and language therapist assistant who was conducting introductory eye-gaze technology sessions with Thomas.

6. Ethnomethodology and Conversation Analysis

This research primarily relies upon ethnomethodology and conversation analysis, a related methodology. These methods are discussed in this chapter. Ethnography is also used throughout. This is discussed in chapter 7, Ethnography. In chapter 9, partial interval recordings and interpretative phenomenological analysis are used. Those methods are outlined there.

6.1 Ethnomethodology

Ethnomethodology (EM) is an approach first developed by Garfinkel during the 1950-60's (Garfinkel, 1967). Ethnomethodology treats activities found in everyday life as phenomena worthy of research and attempts to understand how social order is achieved. This approach, with its emphasis on studying everyday life, varied from the approaches which remained dominant at the time of Garfinkel's writing (e.g. Parsons, 1937) which tried to understand the world in terms of the functions of social structures, value systems and societal norms. This prevailing focus on macro topics meant that the detail of how everyday actions are organised and understood and how shared meaning is achieved were neglected.

Garfinkel suggested that people make sense of their social worlds together and that this sense-making process relies upon the unfolding of any interaction; that shared social procedures are used to make joint sense and establish mutual understanding of the immediate social world. He referred to such procedures as 'ethnomethods' and the study of these 'ethnomethods' as 'ethnomethodology' (see Heritage, 1988; 1998, for summaries of Harold Garfinkel's contribution to social theory and knowledge). Ethnomethods involve people drawing upon their background knowledge and taken-for-granted understandings to both navigate and accomplish social action.

6.2 Conversation Analysis

6.2.1. Development of CA. Born out of the work of Garfinkel (1967) and Goffman (1959; 1983), Harvey Sacks, in collaboration with Emanuel Schegloff and Gail Jefferson (Sacks, Schegloff & Jefferson, 1974) pioneered Conversation Analysis. Prior to Sacks, models of language and action had either relied upon the assumption that people's

behaviour and talk were random, lacking sufficient order to be a topic of study or were explained by idealised models, neglecting the study of *what actually occurs* (Atkinson, Heritage & Oatley, 1984; Heritage, 1998).

Goffman's early work (1959) focused on how people present their "self" to others and how that affects the way in which others orient towards them. He was interested in how the "self", and its presentation, influence social order. Goffman's later work concentrated particularly on the significance of language in everyday social interaction (Goffman, 1983). He believed that there are two types of procedure carried out by talk: system and ritual. System procedures relate to the intelligibility of talk whereas ritual procedures relate to the protection of 'face' and can largely be understood in terms of 'politeness'. Whilst Sacks was Goffman's student, and drew upon both his methods and his work, he did not differentiate between ritual and system procedures (Sacks, 1973). Furthermore, he advocated a data-driven approach, encouraging people first consider the data and engage in "unmotivated looking"; something that Goffman did not do.

Considered a lateral thinker, Sacks developed a new way to analyse conversation. He suggested that to understand conversation, it was necessary to examine recorded naturalistic interactions in minute detail (Sacks, 1984). Influenced by Garfinkel's methodology, Sacks' approach differed from that of other sociologists at the time, most of whom were using macro approaches to study "big" topics (Atkinson & Heritage, 1984). Sacks, however, was interested in any naturally occurring data that he could obtain (Sacks, 1984), no matter how ordinary or mundane.

Conversation analysis provides a method which allows for the systematic exploration of social action and "is a generative method, for a wide range of aspects of the social world" (Hutchby & Wooffitt, 1998, p.7).

6.2.2. Features of CA. Drew (2005) outlined four basic concepts relating to conversation; turn-taking, turn design, social action and sequence organisation. A decade later, Sidnell and Stivers (2012) outlined eight fundamental structures of conversation; action formation and ascription, turn design, turn-constructional units and transition-relevance place, turn allocation and turn sharing, sequence organisation, preference, repair and overall structural organisation. These inter-related features are summarised in turn below.

6.2.2.1 Action formation and ascription. An underpinning principle of CA is intersubjectivity, namely how people find a shared understanding of the world and of others' actions within it (Levinson, 2014). This can be seen to be demonstrated through talk. As Hutchby and Wooffitt (1999) note, "speakers display in their sequentially 'next' turns an understanding of what the 'prior' turn was about" (p.15).

For intersubjectivity to be achieved and maintained, speakers must design their conversational turns so the actions they are designed to achieve are recognizable to the recipients. As Schegloff (2007) acknowledges, action formation relates to how speakers use language, their body and the environment of an interaction, as well as the position of a turn within the interaction, to produce turns which are both designed to be and are recognisable as particular actions. Examples of such actions include requesting, inviting, greeting, accpting, rejecting and so on.

Action ascription, a term Levinson (2014) favoured over action recognition, relates to the recipient's understanding of the previous speaker's action - which action does the recipient believe the speaker is completing with their turn? The term action recognition does not allow for the recipient to be incorrect in their understanding of the perceived action of the speaker, which is why Levinson (2012) favoured the term action ascription. Responding in an appropriate fashion to the previous speaker's turn, for example by accepting or declining a request, demonstrates the recipient's understanding that the original speaker was requesting something within their turn.

People are generally very good at this, making minimal mistakes (although misattributions and misunderstandings do happen – to see how they are dealt with please see the repair section below). However, in English at least, a typically developed person does not wait until another speaker's turn is complete to start processing and planning a response to it. As Levinson (2012) notes, typical gaps between conversational turns in native English speakers are around 200ms (Stivers et al., 2009) but it takes over 600ms to plan and execute the shortest turn (Levelt, 1989). As Figure 3 demonstrates, this means that Person B must begin planning their response to Person A's turn before A has finished their turn. However, B's turn is dependent on A's. B has to establish what A's turn *is doing,* what action is A's turn completing, in order to form a coherent response. For example, if A's turn is an offer, thus completing the action of "offering", then B's response would probably be to complete the action of accepting or declining A's offer.

Identifying the action which A's turn is completing is a prerequisite for the design of B's turn. To be able to respond successfully and coherently, an understanding of grammar is necessary to predict both content and structure (to be able to predict the turn ending and plan an appropriate response).
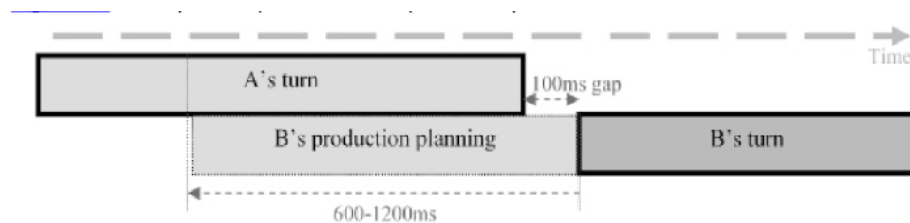
Figure 3 – Understanding and production processes in conversation – (Levinson, 2012).

6.2.2.2 Turn design. Turn design relates to what goes into "building" a turn so that it can complete the action it is designed to achieve. Speakers use a variety of linguistic and non-verbal resources to "build" their turns. As Drew (2012) notes, linguistic resources include lexis, prosody, syntax, morphology, timing, laughter and aspiration. Non-verbal resources include gesture, eye gaze, bodily position and movement.

6.2.2.3 Turn-construction units and transition-relevance places. Conversation generally consists of speakers taking turns to talk, one at a time, which is achieved with minimal overlap and silence (Sacks et al., 1974). As Clayman (2014) explains, a change of speakers is relevant at certain junctures, known as transition-relevance places (TRPs). These occur when a turn is potentially complete. Turns are made up of turn constructional units (TCUs) which are the smallest units which can form a turn of talk (Schegloff, 1996). Turn construction units can be sentences, clauses, phrases or single words. As long as the utterance is coherent, self-contained and recognisable as potentially complete, it is considered as a TCU (Clayman, 2014).
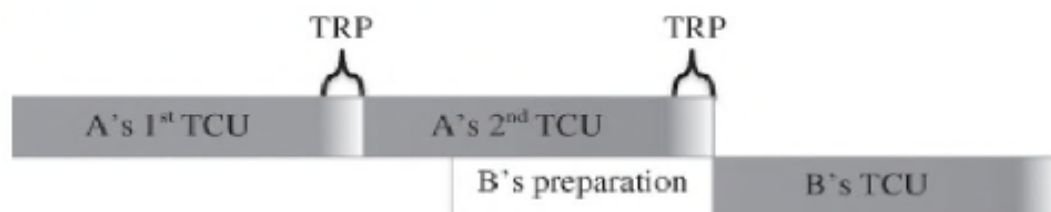
Figure 4 - Turn construction units and transition-relevance places, (Clayman, 2012)

6.2.2.4 Turn allocation and turn sharing. Generally in conversation, people take turns to speak and manage to do this with minimal overlap and silence. In their seminal

paper, Sacks, Schegloff and Jefferson (1974) identified three main rules about how turns are normatively organised:

1) When the current turn reaches its first point of possible completion, if its speaker has selected someone to talk next, then that current speaker should stop at that point and the one who has been selected should begin a next turn there.

2) If, by contrast, at that first possible completion, the current speaker has not selected someone to talk next, then any other party may self-select and begin a next turn, with the first starter gaining rights to the next turn.

3) If, at that first possible completion, the current speaker had not selected a next speaker and no one else has self-selected to take the turn, then the current speaker may (but need not) continue.

There are various verbal and non-verbal speaker selection techniques which enable people to achieve either self or other selection in conversation.

6.2.2.5 *Sequence organisation.* As aforementioned, one of the fundamental principles of CA is that talk is ordered. Items of talk are not produced in isolation to the surrounding talk. Instead, such talk is relevant to what preceded it and what will follow it. As Stivers (2012) notes, "the social actions we perform in social interaction occur sequentially, one following another" (p.191). One of the simplest examples of sequential organisation in conversation is the adjacency pair (Sacks, 1967; Schegloff, 2007).

Adjacency pairs are a pair of turns which occur next to one another, each produced by a different speaker (Schegloff & Sacks, 1973). Each pair has a first pair part (FPP), produced by the first speaker, and a second pair part (SPP), produced by the second speaker (Stivers, 2012). There are established FPP and SPP pairs, such as a summons (FPP) and answer (SPP), offers (FPP) and acceptances/declinations (SPP) and requests for action (FPP) and grants/declinations (SPP) (Schegloff, 2007).

Whilst adjacency pairs are the simplest form of sequential organisation, sequences can be expanded upon. This can occur before, during or after the sequence and is referred to as pre-expansion, insert expansion and post-expansion respectively. Expansions themselves often take the form of adjacency pairs (Schegloff, 2007). An example of a pre-expansion could be a pre-invitation. As Schegloff outlines, when a caller asks "Are you doing anything?", recipients tend to understand this as a pre-invitation, rather than a request for a factual account of what they are up to. Instead it provides

information to the caller about the recipient's stance to the upcoming invitation. This is demonstrated in Figure 5 below.

```
(4.01) JG 3:1 (Nelson is the caller; Clara is called to the phone)
1  Cla:            Hello
2  Nel:            Hi.
3  Cla:            Hi.
4  Nel: Fpre→      Whatcha doin'.
5  Cla: Spre→      Not much.
6  Nel: Fb →       Y'wanna drink?
7  Cla: Sb →       Yeah.
8  Nel:            Okay.
```

Figure 5 – An annotated example of a pre-expansion sequence taken from Schegloff (2007, p.30). 'F' and 'S' denote first and second pair parts respectively, 'pre' refers to the pre-expansion adjacency pair and 'b' refers to the base adjacency pair.

An insert expansion is an expansion which occurs between the first pair part and the projected second pair part. Insert sequences are initiated by the recipient of the first pair part. A simple example of an insert expansion is provided in Figure 6.

```
(6.01) SBL 2,1,8 (Schegloff et al., 1977:368)
1 Bet: Fb  ->  Was last night the first time you met Missiz Kelly?
2               (1.0)
3 Mar: Fins->  Met whom?
4 Bet: Sins->  Missiz Kelly.
5 Mar: Sb  ->  Yes.
```

Figure 6 – An annotated example of an insert expansion sequence taken from Schegloff (2007, p.97, originally appeared in Schegloff et al., 1977). 'F', 'S' and 'b' represent the same things as in Figure 5, "ins" refers to the insert expansion sequence.

Finally, post-expansions are expansions which occur after the second pair part of the base adjacency pair.   These may be minimal post-expansions which end the sequence and are known as sequence-closing thirds. An example may be the use of the word "Oh" to mark that the respondent has received information, or the word "Okay" to mark acceptance of the second pair part (Schegloff, 2007). A further example of this is provided below.

```
(7.07) Davidson, 1984:127 (previously [5.29])
1 Ali: F    -> You wan' me bring you anything?
2               (0.4)
3 Bet: S    -> No: no: nothing.
4 Ali: SCT -> AW:kay.
```

Figure 7 – An annotated example of a post-expansion sequence taken from Schegloff (2007, p.121, originally appeared in Davidson, 1984). 'SCT' refers to sequence closing third, which is a simple, minimal type of post expansion sequence.

6.2.2.6 Preference. In some adjacency pairs, there are alternative SPPs. If an offer is made, the SPP can be to accept or decline the offer, assessments can be agreed or disagreed with, and requests for action can be granted or declined. Although these are alternative responses, they are not equivalent. The design of acceptances, agreements and grants is different to that of disagreements and declinations (Hutchby & Wooffitt, 2008). Pomerantz (1984) studied the structural features of turn design, differentiating between the structure of agreements and disagreements. Her results demonstrated that agreements are largely straightforward and are produced without delay whereas disagreements are delayed and accounted for. Such differences can also be seen with other adjacency pairs (Hutchby & Wooffitt, 2008).

These differences in turn design are referred to as preference organisation. Preference here does not refer to the psychological motives of the second speaker but to a course of action which aligns with that suggested by the first. Second pair parts that align with the course of action of the FPP are referred to as preferred and SPPs that do not are disprefered.

6.2.2.7 Repair. To achieve social action, intersubjectivity must be achieved. Speaker intersubjectivity is threatened when there is potential interactional 'trouble' (Schegloff, 1987). Examples of trouble include problems with articulation or hearing, difficulties finding words, use of incorrect words, recipients having difficulties in understanding or recipients having an incorrect understanding of what the original speaker meant (Schegloff, 1987). When trouble occurs within an interaction, interactional work is done to enable the interaction to continue and maintain or restore intersubjectivity; this interactional work is known as repair (Kitzinger, 2012).

As Kitzinger (2012) exemplifies, repairs can be categorised both by who initiates the repair and who produces the repair. Repair is most often initiated by the speaker of the trouble-source but can also be initiated by a recipient. Self-initiated repair means that the speaker of the trouble-source both initiates and produces the repair. By contrast, other-initiated repairs are initiated by recipients, but it is usually the speaker of the trouble-source who produces the repair.

6.2.2.8 Overall structural organisation. The overall structural organisation of interactions has received relatively little attention.   Specific parts of interactions such as openings (e.g. Schegloff, 1968; Stokoe, 2016) and closings have been addressed (e.g. Jefferson, 1973) but generally only part of the unit of a single conversation is examined (Robinson, 2012). However, more recently researchers are trying to 'map' phases of activities (e.g. Fitzgerald, 2017). Whilst examining small units of interactions can provide insight into how social action is achieved, as Robinson (2012) explains, actions and talk in the course of different situations, such as making a coffee or hosting a dinner party, may only be fully understood if their overall structural organisation is examined. This is often done when people research particular institutional contexts, and how the business of those institutions gets done (e.g. Fitzgerald, 2017).

6.3. Analysing Non-Verbal Aspects of an Interaction using CA

Conversation analysis has provided insight into how the use of non-verbal behaviours are used in interaction (see Streeck, Goodwin & LeBaron, 2011 for an overview). The aim of conversation analysts is to uncover how social action is achieved. Within the typically developed population much social action is achieved through conversation but this is not the sole concern of all CA researchers. It is now accepted that social action is achieved using verbal, bodily and material resources (Heath & Luff, 2014). Embodied actions can be used *as* conversational turns or *alongside* a verbal exchange (Kendon, 2004). Examples of areas of interest have included gaze direction (Goodwin, 1981; Rossano, 2012), hand gestures (e.g. Schegloff, 1984), and body posture and movement (e.g. Heath, 1985; 1986).

6.4. Conversation Analysis Involving People with Intellectual Disabilities

I believe that conversation analysis is a useful method for examining interactions involving people with intellectual disabilities, including those with severe disabilities. However, it is important to acknowledge that to a certain extent examining interactions involving people with severe intellectual disabilities violates some of the assumptions of CA. Antaki et al. (2017) note that people with severe intellectual disabilities do not have interactional resources equal to neuro-typical individuals; for example, vocabulary, syntax and prosody are not available. This means that some of the participants in my research

have limited resources to use in the design of their own conversational turns. People with intellectual disabilities also have ambiguous epistemic status. This means that it is difficult to understand the level of knowledge a person with severe intellectual disabilities has about a topic. In addition, cognitive impairments are likely to limit the understanding of others' actions, especially if these actions are subtle.

Despite the limitations which make interactions involving those with severe intellectual disabilities more challenging, shared understandings and attunement to one another are at times reported (e.g. Forster & Iacono, 2014) and interactions involving people with severe intellectual disabilities do exist. This means that shared understanding must, sometimes at least, be achieved. Interactions involving people with severe intellectual disabilities may not always follow the rules of turn allocation and sharing that can be assumed within conversations involving typically developed participants. However, evidence has suggested that very young children, at a similar developmental stage to the participants with intellectual disabilities included in the research here, do orient to turn construction units (TCUs) and turn relevant places (TRPs) (Kidwell, 2012).

Further, just because an interaction does not necessarily involve talk does not mean that the interaction is not sequentially ordered. Originally, Schegloff (1992) suggested that there was no evidence that non-verbal behaviours follow a normative order as talk does. However, as Levinson (2012), accepts, this is a difficult stance to accept when examples of non-verbal adjacency pairs appear to be observable - one person puts an item on a counter, the other person scans it at the till, (Clark, 2006); one person arrives at a door and looks in their bag for some time, another reaches in their pocket, removes keys and then opens the door (Levinson, 2012). Furthermore, Leaner and Zimmerman (2003) demonstrate how very young children achieve and respond to actions, such as teasing, non-verbally.

Despite its ability to cope with both verbal and non-verbal data, using *conversation* analysis to analyse interactions involving *non-verbal* participants with severe intellectual disabilities, is somewhat controversial. However, there is a growing body of CA research which examines interactions involving people from atypical populations (see Antaki & Wilkinson, 2012; Wilkinson, 2014) and very young children who also use early communicative skills (e.g. Kidwell, 2011).

The use of conversation analysis to examine atypical interactions is relatively new (since approximately the mid 90's – Wilkinson, 2014) and begins to take the field in new directions, which "pure CA" researchers may resist. However, Sacks himself challenged what was already available, offering new exciting ways of looking at things. In the several letters he sent to Goode in the early 1990's (Goode, 1994) Sacks encouraged Goode to publish his work, emphasising the importance of his use of ethnomethodology to examine interactions involving deaf-blind children for the human sciences. Although conversation analysis is a systematic approach, even its founder believed in exploring different ways to examine interactions. Likewise, Liz Stokoe, the creator of CARM (Conversation Analytic Roleplay Method; Stokoe, 2014) has encouraged innovative thinking within the field, to ensure that findings are not only interesting but also useful (Stokoe, 2013). The need for additional CA research examining interactions in care homes (Chatwin, 2014) and involving people with communication difficulties in general (Wilkinson, 2014), and in particular people with severe intellectual disabilities (Finlay et al., 2008) is acknowledged.

Using CA allows a fine-grain systematic examination of interactions involving people with severe intellectual disabilities which stays close to the original data (e.g. Finlay et al., 2008). It also allows for the sequence of the participants' behaviours to be situated. By contrast, approaches which simply tally the number of behaviours exhibited over a certain period only allow limited conclusions to be drawn about the use and efficiency of such behaviours to achieve social action. It is important to establish the sequence of behaviours to be able to understand the potential purposes of exhibited behaviours. Conversation analysis provides a method to analyse behaviours, without stripping them of their interactional context. Further, it is a sufficiently dynamic approach that enables the resources which are available to the typically developed participants to be examined without ignoring the limited communicative repertoire and ambiguity in interaction which are typical of people with severe intellectual disabilities (Antaki et al., 2017).

6.5. Conversation Analysis across Disciplines

Sacks (1984) proposed that CA research, conducted by a number of scholars from a variety of different fields, is its own domain which does not easily fit into any other established scientific domain. Although more recently communication studies has begun

to be accepted as a subject in its own right, much of the related research sits within subject specific academic journals or as book chapters (Parry, 2015).   Although I come to this research with a background in Psychology, and have used both qualitative and quantitative methods, CA is not traditionally viewed as a mainstream psychological discipline. This could mean that this thesis, although rooted in the systematic study of human behaviour, may challenge the conventional view of what constitutes as a Psychology PhD.

6.6. Transcription

Conversation analysts make detailed transcriptions which capture many verbal and non-verbal aspects of an interaction. It is important to note that within CA these transcripts are not considered to be the data. Instead, CA relies upon analysing the fine detail of audio or video recorded interactions. Producing transcripts of such recordings is seen as an important part of the data analysis but also allows others, who do not have direct access to the original audio or video data, to follow any analysis that is presented and clearly see how any analytical claims are grounded in the data. Despite the relative complexity of the most widely used CA transcription method (Jefferson, 2004 – see Appendix J), there are an infinite number of phenomena in any given interaction which could be transcribed to various levels of detail (Hutchby & Wooffitt, 2010). Sacks suggests that transcripts must be a "good enough" record of the interaction (Sacks, 1989, p.26). All transcription systems are necessarily selective (Ochs, 1979). I have drawn upon various methods used by various CA researchers to provide a "good enough" representation of the data.

As Luff and Heath (2015) acknowledge, the best method to capture non-verbal aspects of interactions is a matter of debate and there is no one accepted method of transcription (Luff & Heath, 2015). Even within the field of conversation analysis, effectively representing non-verbal behaviours on the page has taken different formats including line drawings (e.g. Finlay et al., 2008), various transcription conventions (e.g. Goodwin, 1981; Rossano, Brown & Levinson, 2009; Heath, 1986), use of photos and turn by turn detailed descriptions (e.g Kidwell, 2012). Whilst conventions are becoming more standardised for embodied actions involving typically developed participants (see Luff & Heath, 2015), such conventions are not always suitable for research involving those with

intellectual disabilities. In this research I draw on several methods used by conversation analysts to best capture the non-verbal aspects of the interaction for the reader. These include anonymised pictures, traditional Jeffersonian transcription and full descriptions of non-verbal behaviours in prose.

7. Ethnography

All ethnographers write about people, generally through direct, face to face research, using the researcher as one of the major research tools. Ethnography tries to study people in their typical circumstances and environments and draws upon the principle that researchers must 'do as others do' to understand other humans. Experiencing others' daily patterns and acting as both an observer and participant within an environment is known as participant observation (LeCompte & Schensul, 2010) and is a key element of ethnography.

Historically, ethnographers would live in an environment for years at a time completing participant observation to try fully to understand the social and cultural milieu of a community or institution (O'Reilly, 2009). However, ethnographical approaches have changed over the years. For practical reasons, such as funding and time, such a holistic approach is not always possible, and it is common for researchers to complete much shorter research which may be focused on an aspect of the people and interactions being studied.

Using an ethnographic approach involves creating and accepting emic, or insider participant, and etic, or outside researcher, understanding of human behaviour (Mallen, 2010). It is the synthesis of these different viewpoints which offers a broader understanding. Although there are several types of reflexivity within ethnography, generally, as O'Reilly (2015) notes, "Reflexivity, in ethnography, has come to mean thinking carefully about who has done the research and how, under what conditions, how it was written, by whom, and what impact these might have on the value of the ethnography produced" (paragraph 1). It is this reflexivity which is central to finding a resolution between emic and etic understandings.

7.1. Using Ethnography in this Research (alongside Conversation Analysis)

When using a conversation analytic approach, as with most research which draws upon qualitative principles, usually it is ideal to minimise the effect of the researcher (Willig, 2009). This has meant that much of the CA research conducted to date has used existing recorded data where neither the researcher nor the recording equipment is present in the environment of the participants. An example of such research is the

analysis of helpline telephone calls (e.g. Schegloff, 1968; Kitzinger, 2011; Bloch & Antaki, 2018). Whilst this allows one type of (mediated) interaction to be examined, other types of interaction, including face to face encounters and specific interactions that do not easily lend themselves to be routinely recorded, are of interest to analysts.   One approach is to ask willing participants to turn on recording equipment when they are happy to do so, removing any effect that the presence of the researcher may have upon the interaction (e.g. Kent, 2012). However, this approach is not without its limitations. Simply removing the researcher does not limit the potential influence of the recording equipment upon the interaction. Whilst it is suggested that conversation analysis is a robust enough approach to deal with data obtained by such means (Drew, 2004; Kent, 2011), there will be a bias within the sample of the interactions available for analysis. For example, if care staff were able to select the interactions they recorded, it is likely they would choose to record interactions which involved activities they felt most capable completing or activities in which service users were most involved. This may mean that certain elements of interactions, such as service user overt resistance to an activity or staff uncertainty about how best to support a service user, would not be captured. This 'trade-off' may suit some research questions, but it is not an ideal approach to conduct exploratory research examining the naturally occurring typical everyday interactions between care staff and people with severe intellectual disabilities. Furthermore, given the nature of care settings, unless blanket consent was gained by all staff, service users able to consent, and all consultees on behalf of those unable to consent, (see chapter 4 for further details), it is likely that someone who had not consented would come into camera shot. To avoid filming someone without appropriate consent, a researcher must operate the video camera and switch it off if this looks likely to happen.

One approach to minimising the effect of the researcher would be to try to be an invisible researcher, to remain silent during observations and filming, acting as closely as possible to a 'fly on the wall'. However, this would have been inappropriate for the research undertaken for this thesis. I was keen to understand fully the culture of the care centres and to be able to observe and capture (and be part of) the typical activities completed at them.   When completing research with vulnerable people, gaining and maintaining trust is paramount. Similarly, Heath et al. (2010) highlight the importance of relationships when gaining consent to video record.   This presented me with a dilemma.

I wanted the insight which could be provided from an ethnographic approach. At the same time, I felt it appropriate to limit the extent to which I contributed to the interactions I recorded. Accepting that any method is imperfect, I tried to strike a balance between acting as a member of the (immediate) community and acting as an invisible researcher. I embraced acting as a member of the staff community wholly during my familiarisation stage and remained quieter and less active when the camera was on, whilst still reacting to direct initiations of others where I was clearly the target recipient. The purpose of this research is to really understand the nature of everyday interactions involving people with severe intellectual disabilities. To achieve this, this research is firmly rooted in systematic conversation analysis, but uses ethnography to enable the opportunity to understand those everyday actions within the particular social and institutional contexts in which they occur.

7.2. Reflective Ethnographic Overview

This section provides an overview of the role of the researcher, an overview of the themes and explains how they were selected.

7.2.1 Role of the researcher. Before discussing the themes, which form the subsequent chapters of this thesis, it is important to acknowledge fully the influence I, as the researcher, had not only on the data collection (as addressed in chapter 3) but also on its analysis and presentation. Ethnographers accept that they themselves have an influence which affects the phenomena they find interesting and the particular audience they write for (Hammersley & Atkinson, 2007). Within this research, decisions had to be made about the subject matter of my thesis, how it should be written, the analysis and the explanations of the findings.

7.2.2 How the thesis is written. I am a dyslexic early career researcher and academic with a broad interest in people and psychology, with a more specific interest in people who may have difficulties conveying or understanding information. I believe that information should be conveyed as simply as possible without sacrificing any of the complexity of the phenomena being discussed.   I hope this thesis will be of interest to a wide range of people and as Hammersley and Atkinson (2007) acknowledge, "No single text can accomplish all things for all readers" (p. 201). My aim is to write this thesis in a

fashion which is accessible to all potential readers without being tedious for experts. Academic writing should be clear and inclusive.

Having a background in both individual differences and social psychology, I am interested in both how individual cognitive abilities and social relationships (and social group memberships) influence people's experiences. These dual interests mean that I have an appreciation of the difficulty in separating a person's individual characteristics from their local, societal and historical contexts. These interests have a bearing not only on my approach to the behaviours of people with intellectual disabilities, but also to those who support them. I am sincerely grateful for the involvement of all of the participants in this research. I have tried my best to reserve judgement on any of my participants. If, as a result of this research, I suggest that there may be a better way to approach an activity or interaction with a person with severe intellectual disabilities than those exemplified in certain extracts, this is not to suggest that the care staff who feature in those examples lack inherent skills.

Instead, I appreciate that the immediate culture of the institutions they work for, the wider social and political environment within which they operate, and their own personal and professional experiences are all likely to have an impact upon their behaviour. Although it is the actions of front-line staff which have the most immediate effect upon interactions with people with severe intellectual disabilities, it is by no means the only factor. Additional focus must be directed towards legislation, policy and clear practice guidelines. Carers do not work in a vacuum. Appropriate resources, status, job stability and training are essential. I also believe that the ethos of a centre is central to effective interactions.

7.2.3 How data is analysed. There are various guidelines about how to conduct ethnographic analysis. However, many ethnographers widely oppose the use of a set of rules or a strict systematic approach when analysing ethnographic data (e.g.Ybema, Yanow, Wels & Kamsteeg, 2009). Whilst some authors argue for more formalized methods to improve the rigour of ethnographic research (e.g. Lecompte & Schensul, 2010), others, such as Hammersley and Atkinson (2007), suggest that being strictly confined to a particular approach could damage the reflective nature of the ethnography, and may limit the extent to which various data sources are used. I adopted an eclectic

approach. The analytical frameworks adopted are discussed in chapters 6 and 9. How each theme was chosen is set out below.

7.2.4 Themes. The themes within this thesis were identified as interesting concepts that regularly emerged within the data. These are known as etic, or observer-identified, themes (Snow, Anderson, Lofland & Lofland et al., 2006). The extraction of such themes can rely upon common-sense knowledge, personal experience, and by borrowing or adapting existing concepts from the literature (Hammersley & Atkinson, 2007). I used all of these resources. Here, I reflect upon the key personal experiences as well as common-sense understandings and relevant literature and policies which influenced my decisions to focus on the broad ranging themes which are examined in this thesis.

When starting this project, I was relatively naïve. I had experience working with children with intellectual disabilities, but my experience spending time with adults with intellectual disabilities was limited. Although I had worked with children with various levels of severity of intellectual disability, most of my time had been spent with children with mild-moderate intellectual disabilities. As I completed this research, and my experience spending time with the population I was studying grew, I also reflected and examined my own views.

Although this research was exploratory, as I was not testing pre-set hypotheses, my over-arching aim was to examine what interactions involving adults with severe intellectual disabilities actually looked like, how they worked and what affects such interactions. I considered this general research question in the light of previous experience, as well as spending time at my research sites and visiting and revisiting my various data sources. These data sources included field notes, interviews, videoed naturally occurring interactions and social care documentation. This led to the formulation of my four main etic themes: vulnerability, relationships, resistance and meal time interactions. How I reached these four themes and their relevance to interactions involving adults with severe intellectual disabilities is set out below.

7.2.4.1 Theme 1 – Vulnerability. The first theme that emerged was Vulnerability. As soon as I began reading materials which related to this project, it was clear that the relative vulnerability of people with severe intellectual disabilities was a major topic to be considered (Social Care Institute of Excellence, 2015). This emphasis is given particular

importance in the context of abuse scandals being brought to media attention over recent years, including the Winterbourne View case study, a shocking case where six members of 'care' staff were jailed for abusive behaviour towards residents with intellectual disabilities (see Hill, 2012 for a short summary). The Winterbourne View case led to a national review of abuse within care settings and how best to prevent it (NHS England, 2012). Now, more than ever, the first thing that it is essential to consider when working alongside people with severe-profound intellectual disabilities is how to protect them; how to appropriately safeguard. This is evident in recent legislation and policy (e.g. Care Act, 2014; Mental Capacity Act, 2005; Deprivation of Liberty Act, 2007).

Ethical and moral considerations, particularly relating to safeguarding people with intellectual disabilities, remained central to all activity in my research. Such activities included but were not limited to: setting out research protocols, applying for ethical approval, reviewing related literature and documentation, attending various staff and volunteer meetings and training, formal and informal discussions with management and staff. As explained within chapter 8, Vulnerability, I fully support appropriate safeguarding. However, I began to feel that, at times, viewing people with severe-profound intellectual disabilities as *always* vulnerable and, more so, *only* vulnerable could have its own limitations. I considered this viewpoint to emphasize the disability, rather than the person.

This does not mean that I adopt a social model of disability - I do not. Within certain publications, including 'grey literature', guidelines and even government papers (e.g. Valuing People, 2001; Valuing People Now, 2009; Parkin et al., 2018, Schwier & Stewart, 2005) there has been a tendency to adopt a social model of disability which suggests that disability is caused by society and how society is organized rather than any differences or impairments in the individual (Oliver, 1983; 1990). This is in contrast to the biomedical model of disability which is based solely upon the biological differences between individuals (Ogden, 2012). Please see Figures 8 and 9 for diagrams which illustrate this difference.
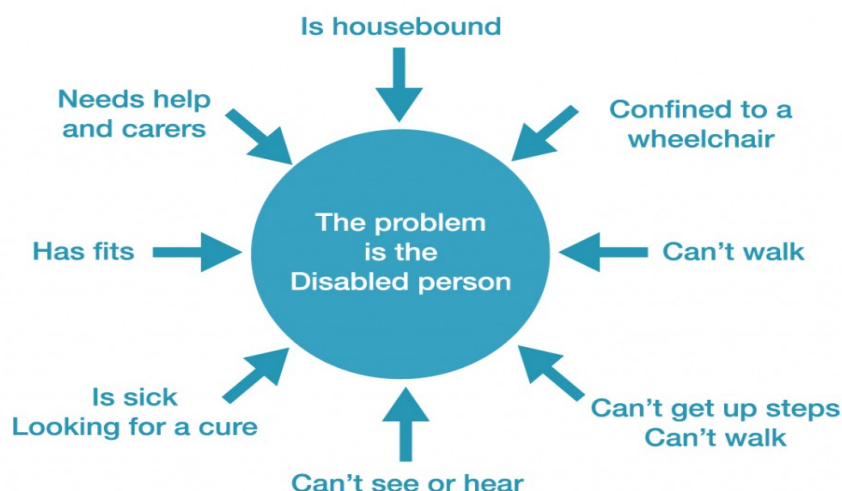
Figure 8 –The Biomedical Model of Disability, taken from Inclusion London (2018).

Figure 9 – The Social Model of Disability, taken from Inclusion London (2018).

The social model of disability has been important in changing the way support is offered and how disability is viewed. However, to ignore a person's limitations due to biological differences, is to ignore important factors which can limit a person's capability

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(e.g. WHO & World Bank, 2011; Shakespeare, 2006). Unless the difficulties experienced by people with disabilities are acknowledged, it is not possible to address them. The model of disability which appears most appropriate is the bio-psycho-social model. The World Health Organisation and the International Classification of Functioning, Disability and Health also adopt this model (WHO, 2001).

The bio-psycho-social model of disability is considered a more balanced approach (WHO & World Bank, 2011), "representing a workable compromise between medical and social models" (p.4). This model accepts the influence that biological, psychological and societal factors have upon a person's health. Interactions between such factors are also modelled. These models are represented at Figures 10.

Figure 10 – The Biopsychosocial model of health – taken from Lakham, (2013).

These models of disability are particularly relevant to this chapter. There are medical risks related to conditions associated with intellectual disabilities. These include choking, aspiration (Chadwick et al, 2003) as well as breathing difficulties and risk of seizures (Bowley & Kerr, 2000). However, the potential vulnerability resulting from severe-profound intellectual disabilities is not only a medical one. People with intellectual disabilities also face increased risks within society (such as marginalization, discrimination, isolation and abuse) and psychologically (such as loneliness, anxiety and

depression). Just as the nature of the disability is multifaceted, so are the risk factors that accompany it. Whether and how these risks are acknowledged, and attended to, was of interest to me.

Care staff appeared mainly to orient to medical risks as opposed to those that may be social or psychological. Even when social and psychological risks were considered it appeared as if both care staff and approving bodies gave immediate risks (e.g. distress), more priority than future risks (e.g. depression or social exclusion). An example of the latter is outlined below.

A condition which was imposed by the Social Care REC was that if a participant with severe-profound intellectual disabilities demonstrated that they were distressed because of being filmed or otherwise being involved in the research, they would be withdrawn from the whole research project straight away. This was not the case for my non-disabled participants who could opt in and out on a session by session basis. It seems as if this consideration was put in place in an attempt to safeguard the participant from both a social risk, not being able to resist activities they do not want to be involved in, and psychological risks of potentially feeling disempowered and distressed. I suggest, however, that this approach could be limiting their capacity to make certain decisions and express certain choices as it limits their ability to make different decisions on separate occasions. It could also entail separate social and psychological risks including exclusion and disempowerment. Within the chapter 8, Vulnerability, this is explored further, and I argue for a more holistic approach to the question of vulnerability and the associated risk assessments.

7.2.4.2 Theme 2 – Relationships. My interest in how relationships influence interactions between people with severe intellectual disabilities and care staff began when I actually started spending time within services and charities that provide support for adults with severe intellectual disabilities.

As soon as I started volunteering at Daisy Way it was clear that certain staff and service users appeared to have closer relationships than others. At that time, I had not formally begun my research and the importance of interpersonal relationships was among the many things I noted about the interactions between service users and staff. It was not until my research began and I started visiting Langley that I revisited this concept.

On my first day at Langley, when explaining that I was there to examine interactions involving people with severe intellectual disabilities, one member of staff said "Oh! You must work with Jenny and Luke!". On seeing Jenny and Luke together I could see why this member of staff had made that suggestion. Jenny's positive behaviours such as smiling, laughing and using high pitched vocalisations appeared to increase in Luke's presence. Likewise, Luke spent much of his time discussing Jenny, her well-being, her care plans, their implementation and so on. To me, at least, he appeared to be her key worker, her advocate and friend. Whilst at first my interest with this pairing was in the hope of capturing particular instances of fruitful and meaningful examples of successful interactions, I soon came to appreciate the need to understand the nature of their interpersonal relationship.

Here I use the term "friend" to mean a relationship which is based upon choosing to spend time with another person, reciprocally choosing and caring about the other and bringing "good" to each other's lives. Knowing each other deeply is also important. This is an adopted version of the definition Hughes, Redley and Ring (2011) settle upon and which they based upon others' definitions of friendship (e.g. Pahl, 2000).

I understand that using the term "friend", when discussing relationships between people with severe intellectual disabilities and those who have developed typically is controversial.   I do not use this term lightly. I have spent a long time reflecting on this during this project. Hughes, Redley and Ring (2011) question how the term "friendship" is used with people with profound intellectual disabilities. They are right to do so.   Many of the authors and policymakers who use the term "friendship" in relation to people with severe-profound intellectual disabilities do so without due consideration of the complexities that accompany it. As they outline, friendships are reciprocal by definition. A typical understanding of the term "friendship" requires qualities that may not be available in relationships involving those with severe-profound intellectual disabilities. For example, it could be argued that the reciprocal nature of such friendships is difficult to establish when they involve people with severe intellectual disabilities or that two people cannot know each other well without being able to talk. Nevertheless, I believe friendships with people with severe-profound disabilities are possible, not least because I consider to have and have had friends with severe-profound disabilities. Within these relationships, I believe we both enjoy each other's company. We, within the context of

their limited speech and mobility and my limited skill, sang and danced together, shared laughter, moments of tenderness and care and, with those who were capable of understanding a changed state, grief. For example, before Thomas's decline in his abilities, after the death of another friend, Thomas and I were sitting quietly, he looked me in the eye for approximately two minutes and slowly said "Miss my friend" and I replied "Me too". He reached for my hand and I stroked his quietly as he maintained eye contact with me.

I made an effort to 'enter their world' and 'learn their language' as outlined explicitly in Caldwell's publications (e.g. Caldwell, 2006) and implicitly discussed in Goode's book "A World Without Words" (1994). Both of these authors focus on rejecting normative ideas of how human interaction works instead focusing on the 'language', communicative and sense-making abilities available to the person. I reaped the benefits of this approach. Spending time with certain people with severe-profound intellectual disabilities I have experienced pure joy. They taught me skills. In times of high stress, I spent times with certain people who enabled me to be in the present, absorbed in other humans and the time we shared together – something, I believe others may wish to achieve. I received feedback from service managers and families of those I felt closest to, about how certain behaviours service users exhibited around me (such as laying their head on my shoulder, sitting close to me or maintaining eye contact) were considered uncommon. I am not suggesting that I formed a friendship with everyone I met with severe-profound intellectual disabilities, far from it. Instead, I suggest that there were a few individuals with whom I felt sure that our relationship, friendship, was somehow special and that they also seemed to demonstrate that.

Of course, the text above would be considered largely anecdotal by most researchers. But, as Hatton (2014) appreciates, researchers can be precious about what constitutes worthwhile information. Anecdotes, he suggests, could be coined as informal personal case-studies, and can be valuable. That said, I understand why anecdotal evidence cannot always be treated as scientific and that common-sense meanings of the world, whilst useful, cannot always be taken for granted as correct.

The relationship I observed between Jenny and Luke was similar to the relationships I believe I experienced with others, but magnified, probably by the length and frequency of their contact. I have tried to evidence, capture and explore the nature

of their relationship in the chapter which covers my second theme, Relationships, which is based on a case study of Jenny and Luke. I chose to use the term "close interpersonal relationship" as Luke knows Jenny in a paid capacity and I did not wish to imply any impropriety.

7.2.4.3 Theme 3 – Resistance. In Theme 2, Relationships, Jenny's behaviours tended to increase from neutral to positive with staff availability, in particular Luke's. However, a lot of the behaviours exhibited by other participants which I observed were not so positive. I also observed people with severe intellectual disabilities pushing items and people away, screaming, thrashing in their wheelchairs, crying and self-harming. In other instances, service users did not engage with the interaction even though their resistant behaviours were more subtle. Non-responses to attempts to engage could be considered as signs of disengagement. However, this was not always treated by staff as resistance.

For people to be able to make decisions and have choice, their behaviours need to be appropriately recognized and responded to. Many texts suggest stopping an activity when a person with severe intellectual disabilities demonstrates they no longer want to engage with it (e.g. Nind & Hewett, 2001; Caldwell, 2006) but few examine and define what such behaviours may look like. This chapter aims to provide some empirical examples.

7.2.4.4 Theme 4 - Mealtime interactions. After observing disengagement and the lack of responses and activity by people with severe intellectual disabilities seemingly being ignored by care staff in theme 3, Resistance, meal time interactions became really interesting to me. They became my 4th theme.

At meal times, disengagement could not be ignored. It was imperative to the activity that the person with severe intellectual disabilities was actively involved. In short, for a person with severe intellectual disabilities to eat or drink, they had to, at very least, open their mouth. As all my participants were supported during meal times, this was an activity which *had* to be co-achieved.

Focusing on meal times also had practical benefits. It meant that the number of people involved in the interactions was limited in comparison to other activities which were completed in groups, such as music, where the number of people involved in a single activity was often much higher. This meant that I was more likely to have consent,

or relevant consultee advice, which allowed me to film the interaction. It was also easier to establish who was talking, or otherwise communicating, and when, which aided transcription and made for a more accurate analysis. Finally, meal times happen regularly, allowing for a significant sub-corpus to be made, which may not have been possible for other activities.

Meal time interaction with people with intellectual disabilities is a topical subject. Intellectual disability researchers have been calling for a renewed focus (Ball et al., 2012; Perez, Ball, Wagner, Clare, Holland & Redley, 2015). My personal experience reinforced that call. For example, when working within a university Language and Communication Sciences department, catering mainly for speech and language therapists my interest only grew stronger. Discussions with academics within this department who had strong interests in eating, drinking, swallowing and meal times in general, reinforced how useful such research could be and that the area was calling out for novel approaches.

7.2.5. An additional overarching consideration: abilities to make responsible decisions. An additional consideration arose when I began to write the first chapters of my thesis, which is relevant to all of my themes. As discussed in Chapter 2, when revisiting the DSM-5's definition of severe intellectual disabilities (APA, 2013), I realised that I was very unsure whether I, or my data, supported the current definition (see Nicholson, 2017). The particular sentence about which I was especially uneasy was "The individual cannot make responsible decisions regarding well-being of self or others" (APA, 2013 p.36). At the very least, this appeared to be in stark contrast to the principles of the Mental Capacity Act (2005). This states that capacity must be assumed regardless of diagnosis until assessment provides evidence to the contrary. Furthermore, assessments are made on a decision by decision basis. It is not proper, or possible, to declare a person incapable of making all decisions.

I reconsidered how my data relates to decision making and to the claim that people with severe intellectual disabilities cannot make responsible decisions. This topic is considered within the context of each theme.

7.2.6. Summary. I concluded that the main questions I would address within my research are:

1.   How is a person perceived to be vulnerable?

2.   How does this affect interactions?

3.   How do care staff and people with severe intellectual disabilities form close interpersonal relationships?

4.   How are these demonstrated?

5.   Do behaviours demonstrate resistance?

6.   How are these behaviours responded to?

7.   How are meal time interactions co-achieved?

8.   Do they follow a certain sequential pattern?

9.   Can people with severe intellectual disabilities sometimes make responsible decisions?

10.   What recommendations can be made for policy and practice based on the findings?

7.2.7 Other observations. One of the hurdles I had to overcome as an exploratory researcher was that I found everything interesting. Even when trying to catalogue video for one theme, I could not resist noticing other issues. In completing this PhD, I developed a new appreciation of how very little has actually been researched, what it is like to explore relatively untouched areas; to do literature searches for topics and find no results. Although every researcher will claim it but this area <u>really</u> begs for future research. So many things I assumed would be widely discussed appeared not to be.

I made notes on topics which could not reasonably form part of this thesis. In Appendix K, I provide a list of questions which have not discussed at any length and are otherwise unrelated to this thesis but were of interest to me and may serve as a starting point for others.

8. Vulnerability

People with severe-profound intellectual disabilities are considered as vulnerable adults or adults at risk. This is because they are likely to meet the following three criteria:

1) Being in need of community care services for reasons relating to mental or other disabilities, age or illness

2) Being unable to take care of themselves

3) Being unable to protect themselves against significant harm or exploitation.

(No Secrets (1999))

Additional safeguards are necessary for groups who are considered vulnerable or at risk. As soon as discussions begin about research, social projects or volunteering opportunities involving people with severe-profound intellectual disabilities, the issue of suitable safeguarding is never far behind. This is entirely appropriate.

People with severe-profound intellectual disabilities need additional consideration to ensure that they are kept safe but here I suggest that safeguarding procedures themselves, both formal and informal, need to be (re)considered in terms of the risks they themselves may create, or at least contribute to. It is important to emphasise explicitly that I do not discourage safeguarding procedures. Instead, I seek to highlight the complexities involved in making some safeguarding decisions and suggest that it may be appropriate to adopt a more holistic view of needs and risks.

Below, examples that emerged during different stages of this research which demonstrate the complexities of safeguarding adults with severe-profound intellectual disabilities are addressed.   First, there is a consideration of a condition of my ethical approval from the Social Care Research Ethics Committee (Social Care REC), related policy and literature. Then examples of the different approaches of staff and family members towards safeguarding participants is discussed. Finally, a conclusion is drawn.

8.1. Social Care REC Condition

This research examined everyday interactions involving people with severe-profound intellectual disabilities, and involved filming both service users and care staff carrying out everyday activities at a day centre and residential centre. As the participants with intellectual disabilities were unlikely to have the capacity to consent, the research needed to be approved by an 'appropriate body' (MCA, 2005). Because of this, I applied to the Social Care REC for ethical approval (see chapter 4).

As outlined elsewhere (Nicholson, 2015) I was unfamiliar with both this ethical review process and research involving this population and my first application was rightly rejected. I then took months to revise my application and necessary documentation and reapplied. The condition from one of the panel members discussed here relates to my second application. My application outlined how the requirements of the MCA (2005) would be met. This included completing assessments and recruiting any participants who lacked the capacity to consent through the use of consultees. As the research was a continuous project during which I would visit the centres regularly over a series of months, it was necessary to outline how to ensure that my participants (non-disabled and disabled) were happy (or at least not unhappy) to be included throughout. In addition to the overall consents obtained for the project, all participants who could communicate a choice/opinion verbally or otherwise symbolically were to be asked before each session whether they would mind being filmed that day. At the end of each session they were also to be asked for permission to keep and analyse the footage. Although the participants were aware of their right to withdraw throughout the project if they so wished to do so, these additional measures enabled participants to opt out of sessions of filming without being withdrawn from the project as a whole.

This protocol was adapted for those who may not be able to communicate their choices symbolically. To ensure that they were happy to be involved, communication passports were to be used and/or developed so that I would be aware of each participant's repertoire of behaviours to enable me to look for any signs of unhappiness or distress related to being involved in the research. Advice would also be sought from consultees, key staff and other staff members/management about whether the participants seemed to show any signs of being uncomfortable during any given session. Routine monthly checks were completed to note any changes to the participants'

behaviours and moods. In addition, a familiarisation period was built into the research protocol. During this time the participants and I got to know each other and towards the end of this period a camera was held but not turned on to allow participants to become used to the camera and myself the time to observe their reactions. Attempts to help the participants with severe-profound intellectual disabilities to understand the purpose of the camera were made by showing them the screen on the camera while switched on and showing them some footage after filming to demonstrate to them that the camera captures movement and sound. Finally, it was proposed that if a participant was considered potentially to be unhappy/distressed about being filmed, the camera would be turned off immediately and the footage from that session deleted. If this happened on more than one occasion the participant would be fully withdrawn from the project.

It was this last point which was challenged by the Social Care REC panel. A member of the panel emphasised their view that participants with severe-profound intellectual disabilities needed to be withdrawn from the project completely as soon as any of their behaviours could be considered as signalling that they would like the camera to be turned off. In the meeting with the Social Care REC, my supervisor and I agreed to the condition, keen to safeguard our future participants appropriately, be considerate researchers and demonstrate that sufficiently to the panel.

Soon after we were granted ethical approval the research began. It was only upon later reflection that my supervisor and I began to mull over the appropriateness of this condition and our unquestioning acceptance of it.

During my data collection phase, several non-disabled participants opted out of specific filming sessions but none withdrew from the project as a whole. Although the participants were not asked why they opted out of a session and were not required to give any explanation for opting out, they often offered accounts as to why they did not want to be filmed on different occasions (as is often the case with sequentially dispreferred responses – Schegloff, 2007) and these were noted. On twelve occasions, reasons were given. Sometimes multiple reasons were given at once, whereas at other times single accounts were provided. The given accounts could be grouped into three categories:

1.   Reasons relating to the session itself

e.g. a new group being run, not wanting to be filmed completing certain activities (such as eating), lack of resources/organisation relating to particular sessions, being short staffed.

2. Reasons relating to personal circumstances outside of work

    e.g. sickness, anxiety about personal concerns, "having an off day"

3. Reasons relating to physical appearance

    e.g. wearing unflattering clothing and feeling overweight.

Some of the same staff members who on occasion opted out of filming would invite and encourage filming of other sessions. Though these participants did not want to be filmed at certain times for a variety of reasons, they nonetheless remained actively engaged in the research. Yet, we had not allowed this same privilege to the participants with severe-profound intellectual disabilities.

Considering the cognitive impairments experienced by participants with severe-profound intellectual disabilities (APA, 2013), some researchers suggest that it may not possible for everybody to express, and indeed form, a viewpoint in the commonly understood sense (Ware, 2004). Ware (2004) does, however, acknowledge that it may be possible to infer the immediate preferences of a person with profound intellectual disabilities but differentiates between immediate preferences on the one hand and views on the other. As Nind (2008) notes, "views are different from reactions, they are opinions, beliefs, standpoints, notions, ideas and they require the person to be an intentional communicator rather than at a pre-intentional stage in which communicative intent is inferred by others" (p.11).   While some people with severe-profound intellectual disabilities may have intentionality, others may not. The ability of people with severe intellectual disabilities to form and express viewpoints unambiguously is likely to be impaired.

To begin to understand whether a preference is time and/or context specific, that is, to understand whether behaviours are a demonstration of immediate preference or a demonstration of a stable viewpoint, the opportunity to express this preference needs to occur at least twice. For example, if a new service user joins a centre and a staff member, unaware of their snack preferences, offers apples which the service user does not eat, there could be a number of a reasons why. For example, it could be that the new service user does not like apples but equally they simply may not be hungry. These are only two,

and there are a number of other, potential explanations. It may be that the service user does like apples and is hungry but what they want to eat is not apples. Alternatively, they may have established a routine where at that time of day they are used to having tea and toast instead. Much of this knowledge will come from spending time with, and having knowledge about, the service user (see Goode, 1994; Martin, Connor-Feleon & Lyons, 2012) but to begin to establish whether this service user does in fact like apples, they will have to be offered apples at least a second time.

Relating this to my research, to be at all confident that a participant wants to be withdrawn from the project as a whole as opposed to just one session, a second attempt to include the participant would be necessary. This does of course come with a risk. There is a possibility that participants could be kept in the research for longer than they wished and could feel disempowered or coerced into completing the research. However, these risks would be minimised by taking the views of others such as care staff or relatives to inform how to interpret behaviours, and through the formal review process.

However, there are certain risks which are so extreme that repeated presentation of stimulus (such as an apple) or a repeated attempt to involve a person in an activity (such as a research project) may not be appropriate. For example, if a participant was to self-harm or pose a risk to others immediately after the presentation of the stimulus/activity then repetition of the presented stimuli/activity would be inappropriate. In contrast, if the reaction is considerably less extreme, such as simply turning away or pulling a face, then a second attempt may be acceptable. Future researchers and intellectual disability experts should focus on creating a set of criteria against which an assessment can be made whether repetition of the presented stimulus/activity is acceptable. It is also important to consider that there may be risks associated with any actions designed to mitigate other identified risks. For example, whilst in this instance, the condition from the Social Care REC was adopted as a way to ensure that people were not kept in a research project they did not wish to be involved in, there are risks associated with withdrawing a participant if they do not wish to be withdrawn. These risks include:

1. Being excluded from research that they may wish to continue /enjoy being included in.

2. The participant may have limited social experiences with a limited number of people (see Verdonschot, Witte, Reichrath, Buntinx & Curfs, 2009 for a review). Excluding people with severe-profound disabilities from research would mean fewer social experiences and opportunities for social interactions with people outside of their small social networks.

3. Reduced social opportunities could contribute to skills deficits and the negative social attitudes of the general population (Gilmore & Cuskelly, 2014).

4. Further, as Antonak and Livneh (2000) note, restrictive attitudes can create subtle barriers to community inclusion. Such attitudes and barriers both then may influence the development and implementation of policy.

5. Finally, premature withdrawal of participants from research could potentially deny the direct benefits that research can offer (Lai, Elliott & Ouellette-Kuntz, 2006). The potential knowledge and understanding both relating to the individual participant and the particular group to which they belong (here people with severe-profound intellectual disabilities) that could be gained through research could be lost (Gelling, 2004).

When considering whether people should be included in research, the focus has been on whether to include or exclude people from the offset but does not extend as far as to discuss premature withdrawal. This is a topic which so far has attracted little attention in the literature. Also, the literature relating to including or excluding people with intellectual disabilities from research tends to gloss over participants with the most severe intellectual disabilities, with some researchers arguing for the inclusion of people with intellectual disabilities who have the capacity to consent in research without full consideration of how to include participants with severe-profound intellectual disabilities (e.g. Becker et al., 2004). There are, however, notable exceptions to this (e.g. Lai et al., 2006; Cameron and Murphy, 2007). Many researchers have already noted that the strong, over-riding emphasis on protection is likely to lead to exclusion from research which could provide benefits for the participants (Aman & Handen, 2006; Iacono & Murray, 2003; Lai et al., 2006).

Amado, Stancliffe, McCarron and McCallion (2013) acknowledge that it is still unclear how to ensure that people with intellectual difficulties are included and integrated and still kept safe. The challenge, as Lai et al (2006) identify, is how to weigh up conflicting ethical duties relating to involving people with intellectual disabilities in research. This is further supported by McDonald and Kidney (2012) who completed a systematic review of ethics in intellectual disability research which highlighted a general lack of consensus on the topic. They note that there is little guidance on how to weigh up conflicting ethical duties.

When considering withdrawal, it is important that the risks associated it, as well as those associated with the participant continuing to be involved in research, are considered. More generally it is important to assess fully the actions that are put in place to identify and mitigate any further risks to which those actions themselves give rise. These considerations apply not only in relation to participation or withdrawal from research. They also apply in everyday circumstances. Where risk arises, and actions to mitigate are in contemplation, it is important to acknowledge that mitigation actions may themselves give rise to other risks, and to identify and assess those risks. This means that there may need to be a balancing act between different risks for the person with severe intellectual disability to inform decisions in their best interest. This balancing act might best be carried out using a biopsychosocial model and taking account of risks as they change over time.

Figure 11 presents a suggested risk assessment tool which may help to ensure that a more holistic approach to risk is adopted. The use of a form is not to ignore the complexities associated with risk and mitigation, nor to suggest that the consideration of it can be reduced to a bureaucratic exercise. It is designed simply to ensure that attention is paid to a broader analysis of risk and that medical, psychological and social risks all figure in decision making. It is designed to promote systematic consideration of potentially conflicting ethical duties.

Figure 11 – A suggested risk assessment tool

Name ……………….   Names of person(s) completing assessment ……………. Proposed Event………….. Date…………………………..

RISK	L	S	T	MITIGATION	MITIGATION RISK	L	S	T
Social								
					Social Psychological Medical			
Additional Notes								
Psychological								
					Social Psychological Medical			
Additional Notes								
Medical								
					Social Psychological Medical			
Additional Notes								

Notes – L represents the likelihood on scale of 1 to 5, where 5 is highest and 1 lowest

     S represents the severity of the risk if it materialises where 5 is highest and 1 lowest.

     T represents change in effect of risk over time, using the following the following D – decrease; I – increase; C – constant.

There is no absolute answer arising from the use of this tool. It is simply designed to be an aide to meaningful discussion of risk, to take account of risk over time. Each row can be copied and pasted as may times as needed and additional copies of the form can be completed if necessary.

It should be completed by those associated with the care of the service user and used to inform discussion and action to mitigate risk.

8.2. Risks Changing Over Time

When considering how to reduce risk, it is important to recognise that not all risks occur immediately. In fact, it appears as if some of the greatest risks relating to overprotection increase over time. For example, Franklin, Raws and Smeaton (2015), reported that both professionals and young people with intellectual disabilities expressed how over protecting people with intellectual disabilities due to perceived vulnerability throughout their lives contributed as a risk factor to experiencing sexual exploitation. They explain that because people with intellectual disabilities were viewed as vulnerable, they were over-protected which led to having little experience of independent life or relationships. This meant that when they faced new experiences, their lack of knowledge and experience meant that they were less likely to appreciate the meaning of a situation and its potential dangers, and so were put at increased risk of exploitation. Other non-immediate risks which are more directly associated with inclusion in research are listed above. As we consider how best to strike a balance between protecting and including, longer term risks should be considered alongside more immediate risks.

8.3. Different Safeguarding Attitudes

People have different attitudes towards safeguarding adults with intellectual disabilities. McDonald, Keys and Henry (2008) report that there are differences between the attitudes of researchers and ethics committee members towards participation in research by adults with intellectual disabilities. The attitudes of those who completed research involving people with intellectual disabilities (both committee members and others) were more in line with disability rights than those who did not. Additionally, it was demonstrated that there were significant differences between the attitudes of participants who had close relationships with people with intellectual disabilities and those who did not. Those with close relationships tended to be more in line with disability rights.

Examples from my own research demonstrated differences of opinion between people relating to safeguarding. Three are set out below. In the first two, attitudes seemingly differed between staff members on the one hand and family members on the

other. The last example demonstrates differences between different members of care staff. Possible reasons for these differences are suggested.

  8.3.1. Safeguarding Jake. One of the participants with severe intellectual disabilities involved in this research was a man in his 30s named Jake. Jake was a wheelchair user and also had two specialist 'scooters' made for him. These were small wheeled blocks which had been moulded to his shape. They allowed him to move around using his feet to propel the 'scooter'. This equipment was designed to increase his mobility and thereby his independence. In short, he could go and explore areas of a room and objects/people in it as he wished. From observing Jake, it was clear he was often happiest on his scooter. This was also noted by his keyworker, service manager and father. It was also mentioned in his communication passport. Jake's health conditions also meant that he could stop breathing at any time. For this reason it was a safeguarding requirement that two members of staff should accompany him outside the centre, and at all times one staff member with him should be fully trained in how to respond appropriately if Jake was to experience problems breathing or stop breathing all together.

  This safeguard was paramount for the staff members. It was given as a reason why Jake could not take another's place on a community visit and often given as a reason why staff could not leave a room to assist other staff members. Below is an extract which details exactly this and the moments that followed.

  This extract is taken from a longer video and supplemented with ethnographic notes. At the start, in the room there are two members of care staff, Luke and Saheb, and four service users, Jenny, Simon, Jake and one other. I am also present. Amy, another member of staff is in an adjoining room.

1	Amy:	Luke [(1)]
2		[(both Luke and Jenny look towards Amy))]
3	Jake:	°Ur::::gh°
4	Luke:	[Yep]
5		[((leans towards the door))]
6	Amy:	Would you just give me a hand for one moment please
7	Luke:	(.8) Errr (.3) I'm in here with [Jake and Saheb]
8		[((stands up] and walks towards the door,
9		then stops))
10		[Erm (1.5)]
11		[((puts his hands on hips and pulls up his trousers] starts to walk back
12		towards the bed))
13	Amy:	We[ll] (can I) bring Jake back in here [then]=
14	Jenny:	[((turns towards the door/Amy))]
15	Luke:	[((turns around again to face the
16		door/Amy))]
17		=[yea I'll bring 'im back with me]
19		[((gets up and starts to walk towards Jake and the door))]
20	Jenny:	>ugh!<
21	Luke:	((turns around to look at Jenny))
22	Jenny:	[((looks towards Luke))]
23	Amy:	[Cause I [want to-]
24	Luke:	[Jenny one sec y↑ea, just a min ((walks off camera and begins to
25		moves towards Jake's wheelchair. Off camera Luke wheels Jake into the
26		adjoining room))]
27	Amy:	I (.) WANT (.) TO SEE HOW YOU DID IT AS WELL (.) cause I don't know
28	Jake:	°U::::r::::::g::::h° ((3s long))
29		((no obvious responses provided to Jake's turn in line 27))

Figure 12 – Extract 1, Luke and Amy safeguard Jake

At the beginning of this extract, Amy summons Luke from the adjoining room (line 1). After Luke replies to this (line 4), Amy issues a request for help (line 6) which would involve Luke going into the adjoining room. Luke's response in line 7 is marked as dispreferred (Pomerantz & Heritage, 2012; Schegloff, 2007) with both a delay and the utterance "Errr" preceding his talk. He then states "I'm here with <u>Jake</u> and Saheb". This talk acts as an account as to why Luke is not meeting Amy's request. However, he does not mention that Jenny and Simon, both service users, and I, are also present. The specific relevance of Luke being in a room with Jake and Saheb is that Jake can stop breathing at any time and Saheb is not yet trained how to support him if that were to happen. Luke's response to Amy demonstrates that it would be a risk to leave Jake in the room without him there and therefore it is problematic to fulfil her request of helping in the next room.

Amy demonstrates her understanding of this in line 13, where she asks Luke if she can bring Jake to the next room. Luke quickly agrees to the solution of Jake being moved but says that he will bring him (line 17) and walks over to Jake's wheelchair. Luke moves him to the other room without interacting with him. During the transition between rooms Jake produced vocalisations (line 28) which were not responded to.

During this short extract Luke is responsive to Jenny, another service user (for example see his verbal response in line 24). Despite this, there is no attempt made by any of the care staff (Luke, Amy or Saheb) to interact with Jake, the person whose safeguarding is central to the discussion and course of action. At no point does anyone try to ascertain Jake's views about going next door. Neither is he informed of the change that is about to happen or is indeed happening at that moment. The lack of interaction even extends to his vocalisations, potentially communicative initiations, being ignored (lines 28-29).

Here, it appears that Jake is being treated as a safeguarding concern rather than a potentially active participant in the interaction. As evidenced elsewhere in this thesis, Jake can be, and is at times, treated as a legitimate participant who can contribute to the interaction and influence the course of action. In this example it is the safeguarding concerns about Jake which dominate the talk surrounding him and the actions directly affecting him. This is not to condemn staff for their understandable concern relating to Jake's health. Instead, it is suggested that is it important that people are viewed as

potential actors within an interaction regardless of the safeguarding concerns they may raise.

8.3.1.1. Discussions with Jake's father about Jake's behaviours at home

As part of the research there was liaison with family members. Attempts were made to contact family members at the start of the research and then every month to involve them in the review process. Family members varied in how keen they were to talk about their relative involved in the research. Jake's father was always keen to talk about Jake, often giving information that was not directly requested, but which helped paint a picture of Jake's life outside the centre. For example, he regularly spoke of typical adult activities that he completed with Jake, such as going to the pub and spending time on a family farm, which he reported that Jake really enjoyed.   It was clear that Jake's father wished to promote Jake's independence and ensure he was included in typical aspects of family life.   Interestingly, he also detailed how the flats they live in have buttons for the lifts placed especially so wheelchair (or in this case, 'scooter') users could access them without assistance. He reported how Jake was able to move around the flats freely to explore as he wished, independently using the lifts. This obviously contrasted with the behaviours of the care staff who were never to leave him without a fully trained member of staff.

There are several possible reasons for this difference. First, while speaking to Jake's father, it was clear that he was keen to promote Jake's independence. It is possible that family members have a stronger focus on independence than those at the care centre, whose emphasis, due to legislation if nothing else, may be rooted in immediate safeguarding. This leads to a further potential reason, which is that family members are, to some extent, allowed the liberty to act as they see appropriate, without (or at least considerably less) fear of accusation of, or liability for, malpractice. Throughout Jake's social care records and in each care plan for every planned activity (such as physiotherapy or smoothie-making), it is noted that Jake needs to be supervised by a trained member of staff.   His communication passport reads "I must NEVER be left alone, I can stop breathing at any time".

8.3.2. Safeguarding Jenny. The idea that families are likely to have more leeway to involve a person with severe intellectual disabilities in activities with associated risks is supported by Schwier and Stewart (2005). They acknowledge that this may especially be

true at mealtimes. Schwier and Stewart (2005) argue that institutions may be bound by particular and explicit constraints whereas families have more discretion. A potential example of this which often occurred in my data involved Jenny's family sending in rice for her lunch, despite the fact that this went against her speech and language therapist's guidelines. Care staff kept reporting this to Jenny's parents but they continued to send the rice. It may be that her parents have given Jenny rice for several years and cannot see the harm, or that they appreciate that Jenny enjoys eating rice and do not want to deprive her of that despite understanding the associated risks. Yet, the care staff at the centre were unable to provide Jenny with the rice unless the whole meal was blended. This happened on occasion, at other times the rice was substituted for an alternative carbohydrate (such as potato) which was served with the rest of the meal provided by Jenny's parents. This example demonstrates the various ways care staff were not able to take the same "mealtime risks" as family members.

The following example details differences of opinion relating to safeguarding Jenny between members of care staff. It highlights that differences can occur between people with the same role. This example involves four participants, Luke and Emma, care staff and Jenny and David, service users, going to a Chinese restaurant. Extracts taken from this example are presented in chapter 11, Mealtimes. Before going out for this lunch, Luke and Emma discuss the possibility of going to the restaurant with Jenny and David, openly in a busy room at the centre. Ayse, another staff member who is not going on the trip, particularly challenged this idea, suggesting it was too cold for service users to be outside. This is despite the fact it was approximately 10° and the restaurant was only about 5 minute walk away from the centre. Whilst Ayse's intentions appear to be to ensure that the service users were safe, her concerns appear unfounded. Ayse's reasoning seems to rely upon her perception of the service users being vulnerable, without due consideration to either the current circumstances or potential benefits associated with the situation.   How to address differences of opinions about how to safeguard people with severe intellectual disabilities appropriately is a subjective matter. It is difficult to provide clear advice on how best to achieve it. However, it would be advisable, where possible, to consult a number of people, preferably in different roles, when conducting risk assessments. It would also be advisable to ensure that all care staff and professionals working alongside people with intellectual disabilities are aware of the

bio-psycho-social model of health and how that relates to understanding disability and risk. This may help staff view risks more holistically.

8.4. Conclusion

Safeguarding is a difficult issue that is not always black or white but something that is multifaceted and a number of shades of grey. It is hoped that the proposed risk assessment tool (Figure 11) will guide the identification, and balancing, of the competing immediate and longer term risks of over and under protection of those with severe-profound learning difficulties.

The topics addressed on the form are unlikely to have clear answers and additional research on how to address them appropriately is needed. However, they are topics that researchers should be alive to. They should be considered in addition, not as an alternative, to other ethical guidelines and legislation (e.g. the MCA, 2005 and MCA guidelines, 2007).

Although people with severe intellectual disabilities are vulnerable, they are not *just* vulnerable. To suggest that at times people with severe intellectual disabilities may be over-safeguarded is a difficult stance to take. However, just because a topic can be a sensitive issue does not mean it should be ignored. Some matters that raise safeguarding issues are more taboo than others. However, we should aim to bring them into general discussion and begin to minimise the issues relating to them with sensitivity. Such issues include use of touch (Hewett, 2007), intimate desires (Gomez, 2012), relationships with staff members (Forester & Iacono, 2008) and the risks of abuse that accompany all of these issues.

Minimising the immediate risk is not sufficient. If the safeguarding creates further future risks then the method of safeguarding itself must come into question. To address these concerns, gatekeepers who consider safeguarding and ethical issues should adopt a holistic, bio-psycho-social approach which reflects the principles of disability rights (McDonald & Kidney, 2012) and considers both immediate and future potential risks.

9. Relationships

Part 1 – Partial Interval Recording and Interpretative Phenomenological Analysis

This chapter uses different approaches to examine relationships between a service user with severe intellectual disabilities and her keyworker. First, an overview of the topic is provided before the first two methods are outlined, analysis provided and discussion presented. Then, the final section focuses on using comparative conversation analysis. The method, analysis and discussion relating to this approach are provided in this sub-section.

9.1 Overview of the Relationship Literature

Recent years have seen an increase in the emphasis that is placed upon ensuring desirable quality of life for people with severe to profound intellectual disabilities. This is evidenced by government white papers such as *Valuing People* and *Valuing People Now* (Department of Health 2001; 2009). However, as the Profound and Multiple Learning Disability Network (2013) acknowledges, most guidelines tend to focus on people with mild or moderate disabilities without adequate consideration of those with more severe disabilities. Clarity about how to achieve desirable quality of life for people with severe to profound intellectual disabilities is needed.

Quality of Life models are historically multidimensional (Morrison & Bennett, 2006) and Petry, Maes and Vlaskamp (2005) demonstrated that this is also true when applying such models to people with profound intellectual disabilities. As Knox and Hickson (2001) note, close interpersonal relationships are considered integral to a person's well-being. Yet people with learning difficulties have limited access to social networks and few close interpersonal relationships (e.g. Forester-Jones, Jones, Heason & Di'Terlizzi, 2004; Lippold & Burns, 2009). This is likely to be particularly true for people with severe to profound intellectual disabilities.

Despite the multi-faceted nature of a person's well-being, researchers have not always acknowledged the influence that interpersonal relationships have upon a person's emotional state. For example, research conducted by Green and Reid (1996) suggested that the students with developmental disabilities involved in their study were happier when presented with their preferred stimuli. Although they made an attempt to address

the issue of potential overlap between how participants expressed their preference and their happiness, this research did not acknowledge the potential impact which social factors can have upon an interaction. For example, Green and Reid (1996) identify the most preferred activity of one participant as having hugs but do not suggest that this may vary depending on the identity of the person providing them. However, more recent research has acknowledged that the quality of relationships with others impacts upon the quality of a person's interactions (McLaughin & Carr, 2005), both of which are considered to affect quality of life (Petry et al., 2005).

There is a growing body of literature that is concerned with promoting and examining successful communication and social interactions and the intrinsic benefits they provide for people with severe to profound intellectual disabilities, which acknowledges that such interactions may also achieve other developmental or institutional goals (Finlay et al., 2008; Nind & Hewett, 2001; 2012). The link between feelings of closeness with another person and successful interaction is discussed in the literature in both anecdotal case studies (e.g. Nind & Hewett, 2001) and empirical research (e.g. McLaughlin & Carr, 2005). Staff interview research has also addressed relationships between members of care staff and people with intellectual disabilities. Such research has identified that staff report having a good relationship with a person, emotional attachments and knowing a person well as important factors when working with people with intellectual disabilities (Schuengel et al., 2010; Forester & Iacono, 2008; Martin, O'Connor-Fenelon & Lyons, 2012; Lee, 2014). However, tensions exist between these beliefs and the need to fulfil an organisation's expectations in relation to professional practice (Forester & Iacono, 2008). Forester and Iacono (2008) suggest that further research is needed about interactions involving behaviours that could be perceived as contrary to their institutional policies such as developmentally-appropriate behaviours and use of touch. They also note that attachment, although examined in the context of educating children with intellectual disabilities (e.g. Nelson, van Dijk, McDonnell & Thompson, 2002), has not been examined in adults with profound intellectual disability.

The impact that interpersonal relationships have upon interactions has been acknowledged in the literature and interventions have targeted improving rapport and interpersonal relationships (Leaning & Watson, 2006; McLaughlin & Carr, 2005).

Research has also focused on finding suitable assessment measures to assess quality of rapport and quality of interpersonal interactions (Hostyn, Petry & Lambrechts, 2011; Nind, 1996).

McLaughlin and Carr (2005) used three separate measures to assess rapport in their study examining interactions between pairs of carers and service-users with severe developmental disabilities. Staff-service user pairings were measured by rankings given by the service user, by staff members ranking their own relationships and by staff providing rankings for pairings involving other staff members. Pairs included in the research were considered to have "good rapport" or "poor rapport" on all three measures. Those who were considered to have good rapport had interactions that were longer and considerably less likely to have to terminate early because of problem behaviours both in tasks that had high and low demands of the person with developmental disabilities. It was found that pairs with poor rapport completing high demand tasks (as identified through staff interview) were most likely to have to terminate the activity because of problem behaviours. As Guthrie and Beadle-Brown (2006) acknowledge, rapport is hard to define. In this chapter I use McLaughlin and Carr's definition of the term and take it to refer to interpersonal relationship quality.

Guthrie and Beadle-Brown (2006) explored the concept of rapport using focus groups of service users with intellectual disabilities, support workers and other professionals Their findings expanded upon and generally supported the related literature on the topic. For example, rapport was considered to be related to quality of life (Petry et al 2005) and the exhibition of challenging behaviours (McLaughlin & Carr, 2005). Indicators of high and low levels of rapport were also identified. Themes relating to low rapport included people being controlling and dominating, tormenting, showing a lack of knowledge, skill and interest, causing physical harm, being submissive or withdrawn. Themes relating to high rapport included people promoting independence and supporting choices, demonstrations of respect, knowledge and skills, trust and confidence. They also reported about factors that affect people's motivation to build rapport. Factors associated with people with intellectual disabilities were presence of a challenging behaviour, appearance and difficult habits whereas factors associated with care staff were personal problems, poor management, work-associated restrictions and fear of repercussion. While Guthrie and Beadle-Brown (2006) have begun to explore the concept

of rapport between care staff and people with intellectual disabilities, they acknowledge that the area would benefit from interview data. They also acknowledge that it is essential to develop a measure of rapport that is more inclusive of people with profound intellectual disabilities which is not solely reliant on questionnaires and interviews. This study aims to address these identified gaps in the literature.

Johnson et al. (2012) developed a model focusing on key processes which were important in building relationships with people with severe intellectual disabilities. Their five key processes were: recognising the individual, sharing the moment, connecting, feeling good and sharing the message. In 2017, Johnson, Bigby, Iacono, Douglas, Katthagen and Bould, tried to improve relationships between care staff and people with severe intellectual disabilities through an invention based upon these processes. Although the intervention appeared to have some success, the results were variable.

Furthermore, the current literature discusses the importance of good interpersonal relationships but little attention is paid to those which are particularly close. For example, in their research, McLaughlin and Carr (2005) only examined pairs of staff and service users where the staff member in question was consistently ranked to be on the 50th percentile or higher with respect to relationship quality with the service user, relative to all other members of staff. However, they did not discuss the nature of any particularly close relationships, where, for example, all staff ranked a member of staff as having the best rapport with a particular service user (and vice versa). People may have many good interpersonal relationships but fewer relationships that they value as friendships or particularly close. Although it may not always be seen as appropriate to use the notion of friendship in the context of professional caring relationships between staff and those with severe intellectual disabilities, professional interpersonal relationships that are considered to be especially close, rather than just "good" appear only to be discussed in passing within the literature.

A noticeable exception to this is the case study of two women, one of whom has severe intellectual disabilities, presented by Bigby and Craig (2017). Their qualitative research findings demonstrate how the relationship between a volunteer and a service user was mutually beneficial, enriched both of their lives and was necessarily supported by the culture of the organisation. They suggest that the relationship, or friendship as they refer to it, between these two women is based upon "nurturing, affection, shared

activity, reciprocal participation, opening possibilities for change, advocacy and community connections" (p.183).

It is acknowledged that it may be difficult for some people to understand what a friendship involving people with disabilities may look like (Reinders, 2008) and that even for those who may be experienced interacting with people with intellectual disabilities, the use of the term "friendship" is nuanced (Hughes, Redley and Ring, 2011). Please see Chapter 8for a discussion relating to this.

Close interpersonal relationships between people with intellectual disabilities and others have the potential to provide both benefits and drawbacks for those involved (see Goode, 1994). Such close relationships, which appear to be somewhat discouraged in some institutions (Forester & Iacono, 2008), are not adequately discussed in the literature. As people with severe to profound intellectual disabilities are vulnerable adults, it is possible that workplaces want to distinguish clearly between professional and personal conduct to avoid questionable practice. This is probably to ensure that this vulnerable population is safeguarded correctly and that abuse, and the suspicion of it, does not arise. Previous research suggests that work-associated restrictions and fear of repercussion are factors that affect staff and professionals' motivation to build rapport (Guthrie and Beadle-Brown, 2006). I argue that close interpersonal relationships could provide large social and emotional gains and agree with Simplican (2018) that providing support for people with intellectual disabilities should also involve a social and emotional element and should not simply focus upon providing basic practical care. Rather than avoiding a topic through fear of taboo, I suggest that such topics should be respectfully acknowledged and addressed (this is in line with others' opinions on other sensitive topics, e.g. Hewett, 2007). This would allow for suitable, reasoned guidelines to be put in place.

This chapter attempts to explore the qualities of such relationships by using a mixed method approach to examine different elements related to a particularly close relationship between Jenny, who has a severe intellectual disability, and Luke her key support staff member.

9.2 Method

9.2.1 Participants. For this study purposive sampling was used. Luke, the member of staff described in this paper is a 46 year old man. He has worked at the day centre for six years and has over 15 years experience working with vulnerable adults. Jenny, the service-user discussed in this paper, is a 32 year old woman. Jenny is not British and English is not spoken within her family home where she lives with her parents. Jenny has cerebral palsy and severe learning difficulties. She has no speech and does not produce any other formalised language. Instead she communicates using facial expressions, vocalisations, eye-gaze, proximity to people and/or objects, posture and gestures. She is reported to be able to understand basic words in the language spoken in her home (such as give, here, drink) but her understanding of English is less clear. She is a wheelchair user but she is able to move around on her knees. Supported she can walk a short distance.

9.2.2 Procedure. Ethnographic field notes were made by myself, about communication and interaction observed for six hours a week, over a two month period. After this period, I filmed staff and service users interacting while completing different activities. Ethnographic field notes complemented the footage. From these observations and ethnographic field notes, I noted that Jenny and Luke seemed to have a close relationship. Particularly, Jenny seemed to be happier when in the company of Luke. She appeared to vocalise more often and smile and open her mouth widely when in Luke's presence. Jenny also followed Luke around the two service rooms when she was on her knee-pads. Other staff members also commented on this.

To examine this relationship, I measured Jenny's behaviours using a behavioural observation schedule and partial interval recording techniques (Gast & Ledford, 2009) to quantify differences in Jenny's behaviours depending on Luke's proximity. I also collected comments that other staff members made about their relationship from video footage and ethnographic notes. Finally, semi-structured face to face interviews with Luke were conducted to allow for a detailed analysis of the perceived close interpersonal relationship.

9.2.3 Data. A total of 5 hours 55 minutes of sessions and/or interactions involving Jenny were video-recorded. The sample examined consisted of 15 different videos involving Jenny, which were filmed on 9 different days. These videos included filmed physiotherapy sessions, a hydrotherapy session, travelling on the bus, a gardening

session, eating and drinking, an art session and an interactive story session. From this sample, all instances of Luke entering, re-entering or leaving a room in which Jenny was present, or beginning or ending an interaction with Jenny were identified. Jenny's behaviours were observed to examine whether her behaviours changed depending upon whether Luke was near and visible to her. All the incidents occurred in 6 of the videos, each occurring on different dates. The examined videos included Jenny in an interactive story session, in an art session, during lunch time and during a fairly loose unplanned session. The same videos were watched and examples of staff members commenting about the relationship between Luke and Jenny were extracted. All examples were also extracted from the ethnographic notes.

In order to ascertain how Luke experienced the relationship, two semi-structured interviews were completed. Both interviews were conducted in a quiet room in the day centre. The interviews lasted approximately 30 and 50 minutes and Drever's guidelines (1995) were followed.

9.2.4 Observation schedule. The schedule was developed with the intention of capturing Jenny's potentially communicative behaviours in different interactional situations with Luke (see Appendix L). The behaviours included were taken from her communication passport which was already in place at the service, ethnographic field notes concerning her behaviours and short questionnaires which were given out to all care staff who worked with her regularly. These questionnaires were completed at the start of the research to inform a communication profile. Staff were asked to describe how Jenny communicated that she was: happy, sad, annoyed, excited and bored. Information was also collected about how Jenny communicates that she wants something or does not want something, likes something and does not like something. As in Nind's Sociability Observation Schedule (1996) idiosyncratic behaviours were included. Because of issues regarding consent and practicalities of filming, directed behaviours such as looking or moving towards someone were often difficult to analyse because people would be out of shot. For this reason, analysis was focused on facial expressions and vocalisations. In Jenny's communication passport and staff reports "vocalisations" were listed, sometimes with attributed emotions (such as "happy vocalisations") as behaviours relating to positive communication or emotions (e.g. liking something or being happy) and "being quiet" was regularly associated with negative communications or emotions.

This highlights that a lack of behaviours can also be communicative. . However, it is important to note that Jenny's vocal behaviours are not heterogeneous. She has a range of sounds she vocalises, which I originally tried to code but it soon became obvious this was too ambiguous and I decided to simply code when Jenny does, and does not, vocalise. A range of facial expressions were also coded. Of these behaviours, smiling, big smiling and opening her mouth were considered to be positive behaviours, whereas frowning was considered a negative behaviour. Neutral facial expressions were also included.

       9.2.5 Interview schedule. The interviews were audiotaped and then transcribed verbatim and analysed using Interpretive Phenomenological Analysis (IPA). The following questions guided the interview:

1. How long have you known Jenny?

2. Could you tell me a little about her?

3. How do you communicate with Jenny?

4. Are there any differences in the way you and others communicate with Jenny?

5. Could you please describe your relationship with Jenny?

6. Are there any positives and/or negatives of having a close relationship with Jenny?

7. Are there any positives and/or negatives for Jenny of having a close relationship with you?

8. Does the relationship have any effects on staff members?

       9.2.6 Analytic strategy. The overall research design utilised a mixed methods approach.

       9.2.6.1 Frequency counts. Partial interval recording (PIR; Gast & Ledford, 2009) was used to complete counts to examine whether Jenny's behaviours changed according to whether Luke was present or not. These PIRs were completed by examining the video recordings and completing an observation schedule.

       Time samples of between 2.10 and 12 minutes were used with behaviours coded every 5 seconds. As outlined above, time samples were selected because they involved

Luke entering or re-entering an interaction with Jenny. Where possible, the selected samples included video of the following:

<ol type="a">
Two minutes before Luke arrives.
Two minutes after Luke arrives.
Two minutes before Luke leaves.
Two minutes after Luke leaves.

This is not to suggest that all interactions or sessions filmed contained a, b, c and d. For example, an occasion where Luke arrives and stays for the rest of the video would only consist of a) and b). Furthermore, if Luke is passing through a place where Jenny is, he may stay for less than two minutes – then b) and c) would be the same. Finally, if Luke leaves within 2 minutes of arrival and comes back before being absent for two minutes, another two minutes analysis starts again.

The number of 5 second intervals in which particular behaviours occurred was totalled and expressed as a percentage of the total number of 5 second intervals. Lee's proximity was coded as either close and visible or not. Visual representations of the data and percentages are provided. As Morgan and Morgan (2009) summarize, there is no consensus about whether it is appropriate to use tests of statistical significance when utilising a single subject design and no consensus amongst researchers supporting the use of tests of statistical significance about which is the appropriate test to use.

9.2.6.2 Comments about the relationship made by others. Approximately 5 hours and 50 minutes of video were watched for any comments made by other staff members about the relationship between Luke and Jenny. All comments were transcribed and are reported in the results section.

9.2.6.3 Interpretative Phenomenological Analysis. Interpretative Phenomenological Analysis (IPA) was used to provide a qualitative analysis of semi-structured interviews with Luke about his relationship with Jenny. I was interested in how Luke, the care worker, experienced and viewed his relationship with Jenny and why he believed it to have formed. Particular focus was on how they communicated. IPA is a particularly suitable method for the subjective nature of this research (Reid, Flowers & Larkin, 2003). This is because the approach is borne out of the recognition that an individual's reality is interpreted. Instead of viewing reality as objective, IPA

acknowledges that experience is filtered through an individual's interpretation and perception, which will be influenced by the interests and backgrounds of the individual (Pietkiewicz & Smith, 2014). The research findings therefore will be influenced by the interests and social and cultural backgrounds of the researcher. As Willig (2009) notes, when using IPA the participants' experience is always interpreted by the researcher. My interest in trying to better understand the nature of strong relationships between care staff and service users and their communicative and interactional consequences for those with severe to profound intellectual disabilities will have influenced the questions asked and taken the analysis down particular avenues. However, it is worthy of note that from the semi-structured interviews, themes emerged from the participants' responses which were not purposefully based on any preconceptions of the researcher.

The transcript was read several times and notes were made about significant topics that emerged. From these notes, themes were identified. These were then organised into clusters of related themes and were checked against the transcript again to ensure that the analysis reflected the participant's account. Relationships between themes and/or clusters were also established. This is in line with Smith & Osborn's guidelines (2003). However, it is noteworthy that although Smith & Osborn's guidelines (2003) were followed, I was mindful of the comments of Larkin, Watts and Clifton that researchers using IPA should not only attempt to summarise a participant's beliefs, experiences and concerns but also aim for a richer, conceptual interpretative analysis (Larkin, Watts & Clifton, 2006).

9.3 Results

9.3.1 Frequency counts. The percentage of the time Jenny spent vocalising was higher when Luke was close and visible (83.2%) than when he was not (59.1%). Additionally, the percentage of time Jenny spent displaying facial expressions that were interpreted by other staff and me as positive was also higher when Luke was close and visible. This was true for smiles (43.6% and 23.9%), big smiles (47.2% and 11.5%) and Jenny opening her mouth (56.5% and 22.5%) .
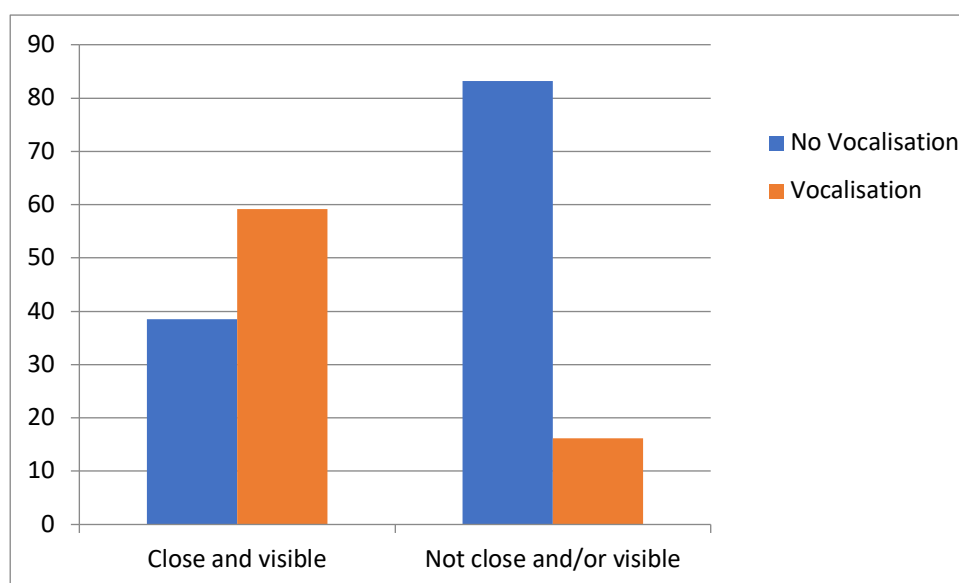
Figure 13 – A graph demonstrating the percentage of time Jenny spent vocalising
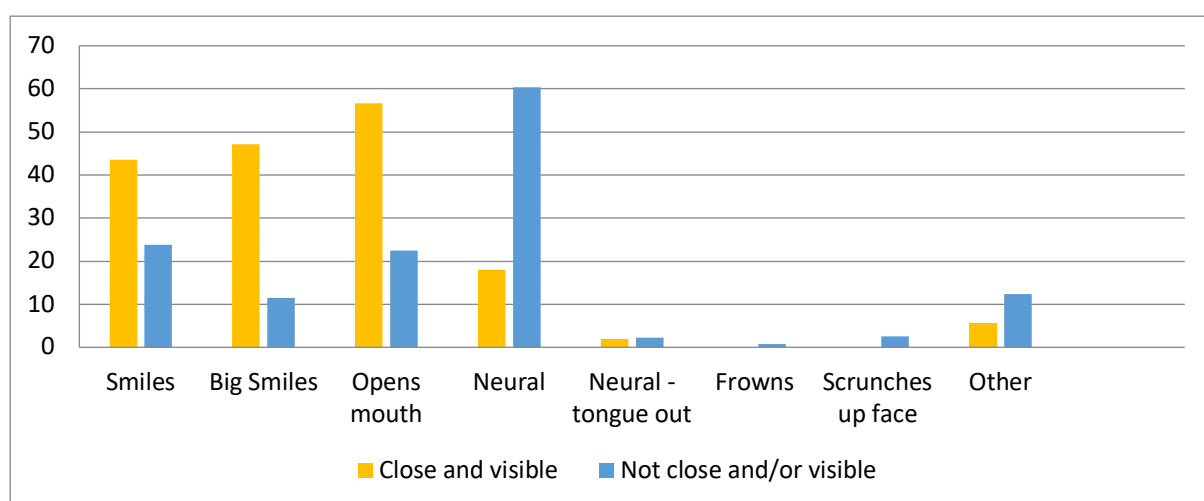
Figure 14 – A graph demonstrating the percentage of time Jenny spent displaying different facial expressions when Luke was close and visible and he was not.

9.3.2 Comments about the relationship by others. Five comments were made about Luke and Jenny's interpersonal relationship by other staff members during approximately 5 hours and 50 minutes of naturalistic video data. These comments have been transcribed and are presented in Figure 15.

	Other staff comments	Context of the situation

1	"He's coming back!"	Just after Luke leaves the interaction and Jenny looks towards him.
2	"Get your eyes off him"	Luke is not involved in the interaction but is visible and Jenny's eye gaze is towards him.
3	"Why are you going over there? Luke's not in there y'know"	Jenny is being supported walking with another care-worker and walks towards a door.
4	"Oh you want me now he's not here"	Jenny initiates an interaction with a key worker during a morning session. Luke is not present but had been in the room earlier.
5.	"Wait, he will come to you"	Jenny is moving around on her kneepads and is persistently trying to move towards Luke.

Figure 15 - Comments that other staff made about Jenny and Luke's relationship

No comments were made specifically about either Jenny's or Luke's interpersonal relationships with other staff or service users with the exception of staff commenting how Jenny was "surrounded by too many of her [your] people, all too exciting" in a gardening session. Luke was in the room, but so were 4 other staff members.

The comments suggest that Luke and Jenny have a relationship that is noted by other staff members, while her relationships with other staff do not attract such comments. These comments make reference to Jenny's desire to spend time in the company of Luke and to her non-verbal behaviours that staff appear to interpret as conveying meaningful information about their relationship. For example, Quote 2 makes reference to Jenny's eye-gaze. Quotes 3 and 5 imply that Jenny does not only desire Luke's company but also tries to seek his company out. This complements Quote 4 which supports the view of the researcher that Luke and Jenny had a particularly close interpersonal relationship.

9.3.3 IPA. Five main themes were identified from Luke's responses in the semi-structured interviews. These themes consisted of clusters of categories and sub-categories which are hierarchically organised. Appendix M sets out the main themes, themes and sub-categories identified and their thematic levels.

9.3.3.1 Main theme 1 – Using appropriate communication methods. Luke
emphasised the importance of appropriate communication methods in establishing a close interpersonal relationship with Jenny. Sub-themes of this theme reflect both that appropriate communication allows positive interaction(s) and that failure by others to adapt suitable communication methods caused barriers to the development of good relationships and communication. Important adjustments to communication included using words in her language and non-verbal communication methods.

Appreciation of Jenny's abilities and limitations was integral to this theme. Luke reported that appreciating what Jenny was, and was not, capable of doing and understanding allowed him to adjust his behaviours accordingly. For example, he said "I like to get into Jenny's way of communicating – you know, the staff member is always going to have to adapt the service to the user in my opinion". He discussed how Jenny fulfils requests when asked in her own language, but questioned the assumption which he believed other staff to have made that she can understand English. He suggested that when Jenny appears to be responding to requests made in English, instead she may be responding to visual cues. He illuminated this with the example of Jenny co-operating with staff when supporting her to put her coat on. He explained "I'm not so sure that she is responding to "Let's put your coat on Jenny" said in English. She's got the common sense to realise that you are presenting her with her coat. So that's a visual cue for Jenny". Although all staff are obviously aware that Jenny is not capable of verbalising requests, Luke noted that staff do not always appreciate that people need to adapt their ideas about communication to provide Jenny with adequate responses to her actions; "Jenny doesn't have the ability to say 'Can you get me out of this chair please?' I just don't know how people think she is going to".

Throughout both interviews Luke regularly referred to a change that he had implemented at the service, ensuring that Jenny was out of her wheelchair when spending time at the centre. Jenny had previously displayed challenging behaviours when left in her wheelchair but Luke viewed this as a request to get out of the chair, expressing that "challenging behaviour is just a type of communication". Although as can be seen from the coat and wheelchair examples above, Luke discussed potential misattributions which other staff members appear to experience interpreting Jenny's idiosyncratic communication, he also referred to various non-verbal methods which Jenny uses herself

to communicate which in his view are clear and largely unambiguous. These include vocalisations, facial expressions, body movements, physical proximity and physical contact as well as challenging behaviours such as thrashing about and trying to bite others. For example, when asked about how he formed the impression that Jenny had favourite staff members he replied, listing her non-verbal behaviours, "Jenny shows that quite clearly who she chooses to gravitate to and who she smiles and laughs and screams for".

9.3.3.2 Main theme 2 – Jenny's rights.

A further theme that emerged from the data was that Luke respected Jenny's rights. These rights included the right to be free to make choices, and the right to be responded to and have positive interactions. Luke also discussed acting as Jenny's advocate and difficulties he experienced supporting Jenny's rights within the team.

Jenny's mobility was a key right that Luke referenced several times. He used this example to demonstrate how it was necessary to respond appropriately to Jenny's behaviours.   He stated that in his view Jenny's behaviour often expressed her wish to get out of her wheelchair and that he would respond by supporting her out of the chair as much as possible stating "it was obvious that she didn't want to be in the chair. So I don't know if you notice now, she's out of that chair immediately every morning". He identified Jenny's right to express her choices and to be responded to "even though she may approach the same individual a lot of the time, it's still a choice and freedom that she never used to have to be honest".

However, although he believed that Jenny's rights to choice and to act freely should be paramount, he acknowledged that it could cause difficulties for other staff. Working in an institution that organises certain staff and service users to work together for particular sessions means that when Jenny exercises her choice to spend time with Luke, it may disrupt the work of other staff members. Luke expressed this stating "I can see the difficulties for others when they're trying to work with her and she's made that decision to go off and see someone else but you know, I haven't got a problem with it because she's exercising choice". He also offered potential solutions to overcome these difficulties, including staff making more effort to engage with Jenny, suggesting they should "Give Jenny a little bit of attention. It goes a hell of a long way and it's one thing you should be doing anyway".

He noticed that Jenny exhibited more challenging behaviours with staff members who do not always transfer Jenny out of her wheelchair when returning to the main room of the day centre. He commented "I can assure you she wants to get out of the chair, and that behaviour has gone the moment she is out of the chair". It is likely that staff members may vary in their appreciation of Jenny's rights and that people who are more sensitive and/or aware of Jenny's rights may be more likely to respond to her behaviours than those staff members who may place less value upon it. Luke explains that for him "that's her freedom as far as I am concerned in that room and if she's not being supported to get out of her wheelchair then she is not being given the opportunity to mingle, go see who she wants, have that freedom of the room". It may be because responding to Jenny's choices creates difficulties for some staff members that they fail to recognise her right to express a choice and receive an appropriate response. Luke alluded to this when he commented on the relationship between Jenny's behaviours and whether her choices are acknowledged "I mean, that behaviour's gone the moment she is out of that chair, so it might be a behaviour that people are having trouble managing, but for me, it's easily managed by supporting her to do what she wants, which is getting her out of the chair".

It also emerged from the interview data that Luke often acted as Jenny's advocate Luke's responses demonstrated that he would continue to brief what he considered Jenny's requirements if they were not being met by other staff members "I've briefed, it's one of my frustrations here - I've briefed on countless occasions that Jenny is to come out of her chair". However, it appeared that he felt some conflict between encouraging others to act in Jenny's best interests and being a supportive member of the team, as he finished his sentence offering a (relatively weak) explanation for why people may not fulfil his request at briefing, stating "but you get those moments where people forget or something". Later in the interview, he offered other reasons why staff may not want to support Jenny out of her wheelchair namely lack of physical strength and insufficient training. Yet, Luke also continued to discuss his frustration about his briefings being ignored. For example, he comments "and you know, I've briefed that God knows how many times".

9.3.3.3 Main theme 3 – Rapport building. The third theme that was drawn from the analysis is rapport building. This theme encapsulates the personal qualities of both

Jenny and staff members which enable rapport to be built. It also refers to the qualities of a relationship between two people with particularly good rapport.

Luke suggested that good relationships consist of (at least partially) "positive interactions", "just building that trust… that confidence" and seeing each other frequently. He also acknowledged that some of Jenny's qualities, such as being a "happy", "warm" "positive" person with a wider communicative repertoire than other service users means that "she has the ability to form relationships more". Luke compared Jenny to other service users, explaining that he liked the positive feedback that she provides and her active part in their relationship: "An example - Lee and Scott, sorry to give examples, they, they don't… you would get no eye contact or acknowledgement facially or anything that you would consider clear acknowledgement that you're interacting with them, if you know what I mean. Jenny will certainly know you're next to her and she'll let you know (laughs). She'll grab you!". This demonstrates that he finds interacting with people who lack certain communicative behaviours more difficult and/or less enjoyable because of the lack of feedback the interaction provides. He contrasts these problematic interactions with interactions to those he is able to enjoy with Jenny, highlighting her communicative behaviours which allow her to provide Luke with feedback and be an active member of the interaction.

Although Luke discussed experience, knowledge and ability as important factors when supporting Jenny in general, when specifically discussing factors that staff need to form good relationships with Jenny, his main focus was that staff need to put enough effort into interacting with Jenny and "if they are not showing any interest in her then she's not going to show any interest in them", offering the advice "smile at Jenny and she might smile back at ya". Luke even goes as far as to state that "Jenny is just gravitating towards what's, you know, right."

9.3.3.4 Main theme 4 – Representation of the relationship. This theme consists of two subthemes: Luke's representation of the relationship – professional vs. personal and uncertainty regarding Jenny's representation of the relationship.

Luke's responses during the interviews strongly suggested that the relationship between him and Jenny had both professional and personal elements. He described their relationship "as first and foremost professional" and regularly prefaced his responses with "as Jenny's keyworker…". Additionally, Luke discussed duties which he

carried out as Jenny's keyworker including "liaising with all the professionals, speech and language, physiotherapists…", "to be a point of contact with carers and family" and helping sort out practical issues such as being "involved in the implementation of, and the devising of, her programme of activities". He also often discussed his other key clients and when discussing his close relationship with Jenny even offered reasons why he may not have as close an interpersonal relationship with them: "My other two key clients only attend three days a week whereas Jenny attends five so I tend to see Jenny more than the others".

When questioned about whether there was an emotional element to their relationship, Luke replied "Maybe on Jenny's part. Maybe". He continued to state "My relationship with Jenny is predominantly, it's professional" Although this may appear that Luke originally denied feeling emotionally attached to Jenny, he later alluded to their relationship including an emotional element with remarks such as "I have developed a positive relationship with Jenny", and that he "always enjoyed interacting with Jenny wholeheartedly, she's so,… so positive" and comments that she is "a very, very good natured individual, generally happy, smiling". The warmth with which he talked about her was evident. Whether or not Jenny was his "favourite" at the centre, which was raised a number of times by Luke, was not straightforward. He acknowledged that "Jenny has the ability to interact with people far more than some other individuals, so she has the ability to form a relationship more". He appeared to summarise the conflict he experiences about trying not to show favouritism while engaging in a close interpersonal relationship with Jenny – "I don't try to show favouritism to them. But we do work with people and therefore that can be a very, very, difficult hurdle to get over".

Despite stressing the practicalities in their relationship, and attributing emotional attachment largely to Jenny, he later spoke of his "fondness" for Jenny and refers to their "strong bond". He questioned the extent to which Jenny can really understand the nature of their relationship - "Jenny doesn't have an understanding, perhaps, I think it's a bit different to be sure of Jenny's understanding of relationships with people" and later noted "people do need to be wary of Jenny's boundaries as her boundaries would not be as clear as our own". I interpreted these comments to allude to the possibility of Jenny being over-involved in their interpersonal relationship, possibly attributing romantic attraction, or a "crush", to it. Luke suggested that Jenny's preference for some staff over

others was obvious, remarking "it's a clear message who she likes, an absolute clear message who she likes".

9.3.3.5 Main Theme 5– Benefits and potential disbenefits. This final theme

focuses on potential benefits and disbenefits that are caused by the close interpersonal relationship between Jenny and Luke. Three sub-themes are identified. These are perceived potential benefits and negatives relating to 1. Luke, 2. Jenny and 3. Others.

When Luke was asked explicitly, he denied that there were any potential negative aspects to the relationship for him. This could be because he regards the relationship so positively that negative aspects seem negligible. Alternatively, it may be that this question touches on a sensitive topic for Luke, which he does not wish to discuss directly. However, Luke did discuss negative aspects associated with his relationship with Jenny. As discussed in Theme 5, Luke experiences a struggle with the team when he acts as Jenny's advocate (a benefit the relationship provides for her). He also stated that he feels as if he is unable to leave his job - "I think sometimes I feel a little bit trapped in this job as well because I'd feel like I was deserting Jenny, Dave and Lee (other key clients) if I left". Although Luke has included all his key clients here, he made this statement after talking particularly about Jenny's reliance upon him. For Luke, these negatives appear to be outweighed by the positives of their interpersonal relationship which are job satisfaction and enjoyment.

Benefits of the relationship for Jenny which Luke identified include having an advocate, enjoyment, physical contact and development by participation with him in activities. Being an advocate for Jenny is a central theme which is most clearly exemplified by changes Luke has implemented regarding the use of Jenny's wheelchair. He said that he continues to try to implement such changes for her benefit. Working with a person with whom she has a close relationship also benefitted Jenny because it made completion of certain tasks more enjoyable. Luke reported "she's very, very, very much a person-focused individual rather than a task focused individual. When she is doing physio it's all the contact side of it with the people she likes that she loves and she enjoys it so much she doesn't, I don't even think she realises how much work she's actually putting into her physio programme". This quote demonstrates both how Jenny gets enjoyment from being in the company of Luke and that this perceived enjoyment (of the interaction and physical contact they share) enables her to complete activities that benefit her health

and mobility. Luke summarised this point stating "I find that because I have that bond shall we say with Jenny, it enables me to help her develop more".

A potential negative for Jenny included becoming over reliant or fixated with Luke and, as Luke discussed, related to her extreme unhappiness at being separated from him. When commenting on Jenny's positive relationships with newer members of staff Luke said "I am actually quite pleased about, because I did have a concern that Jenny was perhaps too fixated on myself but that's not the case". He also noted that "It is important that Jenny does work with more individuals and she shouldn't be so, you know, 'cause when someone leaves, she's got to, you've got to remember that she's accessing a service here and staff rotation can happen and they're not always going to be there".

There is also an implied lack of focus by Jenny in sessions when Luke is absent, which was only discussed in terms of difficulties for other staff members, but may also have direct disbenefits for Jenny if the activities were developing life or physical skills. An additional potential negative for Jenny is related to Luke's feeling of being trapped in his job. There is a high possibly, particularly with the current reforms of state provided services, of an eventual loss, if not of all contact, at least of the relationship in its current form. Luke is aware of this potential negative but expressed that it has been mitigated by the recent formation of good relationships by Jenny with new staff members.

Potential benefits for other staff members include explicitly, and possibly implicitly, learning from Luke about Jenny. Luke said that he is happy to teach other members of the team how to support Jenny appropriately. For example, he referred to the possibility that other staff may have difficulty in getting Jenny out of her wheelchair because they did not know how to do it properly. He stated "If people are a bit uncertain or unsure just voice it and I'll come over and help, yeah, demonstrate". Here he is talking about sharing a practical and trainable skill but obviously this is not the only way by which staff learn from one another in work teams. Staff may also learn implicitly from the example provided by the relationship between Jenny and Luke.

Potential negative impacts for other staff include experiencing problems meeting institutional goals (such as completing a set activity) because Jenny is likely to seek the attention of Luke. Luke acknowledged that Jenny leaving another member of staff to go in search of him may be "difficult for that staff member". However he was not explicit

about whether he means that causes practical problems or emotional difficulty for the staff member concerned. It is possible (and perhaps likely) that he meant both.

9.4 Discussion

9.4.1 Frequency counts. There were observable differences between the behaviours Jenny exhibited when she was, and was not, in the company of Luke. She displayed more behaviours associated with being happy, namely smiling and (happily) vocalising when in Luke's company.

In line with previous research, using observational schedules to analyse behaviours seems an appropriate way to assess the behaviours of people with severe-profound intellectual disabilities' (Green and Reid, 1996; Nind, 1996) and may be a way to include people with severe-profound intellectual disabilities in the assessment of quality of relationships (Guthrie and Beadle-Brown, 2005).

However, although this change is discussed in terms it marking her relationship with Luke, the findings in this study are also interpreted to demonstrate an increase in Jenny's happiness (Green & Reid, 1996) and sociability (Nind, 1996). The overlapping concepts of happiness, sociability and rapport cannot begin to be teased apart by the analysis of the quantitative data available. The conceptual overlap of these constructs motivates causal questions about how interactions, interpersonal relationships and emotional feelings feed into the development of each other. Such questions would need an in depth longitudinal study regarding the formation and maintenance of close interpersonal relationships in this setting. However, it can be inferred from the findings that Jenny's varied non-verbal behaviours when Luke is at varying proximities is a marker of her personal feelings about him, which supports the opinions held by Luke, other staff members and the researcher. A longitudinal study would also address other related questions. For example, it is worth noting that Luke was Jenny's keyworker and as Hurman (2015) notes, keyworkers often have good relationships with key clients but there is difficulty establishing the causal nature of this relationship without directly studying the formation of relationships. The PIR data demonstrates that Jenny's positive behaviours increase when Luke is in close proximity, but does not allow the conclusion to be drawn that Jenny's positive behaviours increase more for Luke than they do for other

staff member. However, data is provided on this in the CA comparative section later in this chapter and is also supported by staff comments (see Figure 15).

9.4.2 IPA. My decision to focus on the relationship between Jenny and Luke was borne out of noticing differences in Jenny's communicative behaviours and a change in her interactions as a whole when in Luke's company. Although I have attempted to analyse the data and organise the themes to represent the key elements as Luke experiences and represents his relationship with Jenny, it must be acknowledged my interest in communication involving people with severe intellectual difficulties may have influenced my interpretation of the data. However, this case study provides potential reasons why interactions between people with particularly close relationships look considerably different to other interactions, as evidenced by the behavioural analysis.

The results support Guthrie and Beadle-Brown's finding that there are identifiable indicators of rapport. Here, Luke's responses and the analysis suggest that there may be particular personal qualities and/or beliefs which allow for rapport to be built. Further research into these qualities could help identify groups of service users or staff that are likely to struggle to build good rapport with others. Additionally, Luke describes his approach towards using appropriate communication methods and even discusses perceived misattributions of other staff members. This suggests that it may be possible to uncover potential barriers which some people experience in developing rapport, particularly when focusing on staff members' level of rapport with a particular individual. Other tensions are also explored in the representations of the relationship. There are tensions between Luke's experience of professional vs. personal elements of the relationship. Such tensions are typical in caring professions where those involved need to manage their feelings and expressions which are necessary for the job. The specific expectation to manage and regulate emotion like this is known as emotional labour (Hochschild, 1983).

Appreciation of Jenny's rights and acting to try to enforce them by acting as her advocate are related to one another. It appears that Luke's opinions relating to Jenny's rights shapes their relationship. This suggests that the belief system of the staff members is influential in developing relationships with people with severe-profound intellectual disabilities. Finally, Luke's opinions about the benefits and potential negative aspects of

the relationship are provided.   Although all of these findings are of interest, I have expanded upon those that I find most interesting below.

 9.4.2.1 Professional/personal. The topic of professional vs. personal relationships has been a topic that has been explored   in staff interviews in earlier research (Forestor & Iacono, 2008) . Luke's responses in this respect suggest that he experiences a tension between the close interpersonal relationship between himself and Jenny and the professional boundaries that are assumed of a care worker. It appeared evident that Luke was aware of this tension and felt the need to emphasise the "professional" basis of their relationship. I do not suggest that the relationship between Luke and Jenny is anything other than proper, and one which has clear benefits for Jenny's quality of life. It is possible that Luke considers the word "professional" as meaning proper or appropriate and "emotional" may be a term that he associates with relationships that exist outside of his work life and perhaps specifically to describe familial or romantic relationships. Though he is clearly fond of Jenny, Luke's responses indicated his understandable wish not to allow their positive relationship to leave him open to any allegation of being unprofessional. When working with people with severe to profound intellectual disabilities, their social and emotional needs and increased chance of having a limited social network call for care staff to have close interpersonal relationships with service users. Such close proper interpersonal relationships should be researched, accepted and guidelines drawn up about them so that they can be viewed within a professional framework.

 9.4.2.2 More likely to complete tasks without challenging behaviours. Another finding that supplemented previous research was that one of the benefits of the relationship for Jenny was that she enjoyed completing tasks when she completed them with Luke. This supports previous research that suggests that interactions between staff and service users who have good rapport is associated with a lack of challenging behaviours during interactions (Guthrie & Beadle-Brown, 2006; McLaughlin & Carr, 2005). However, Luke's insights offer potential explanations as to why this may be the case. For example, it may be that the service user is more focused on the social and physical interaction or that the challenging behaviours can be avoided by anticipating Jenny's wants and needs. Luke's anticipation of Jenny's wants and needs is rooted in the view

that challenging behaviours are valuable communicative behaviours that should be acknowledged and responded to (Social Care Institute for Excellence, 2011).

9.4.2.3 Enjoys physical contact. Luke reported one of the benefits of the relationships for Jenny was that she enjoyed activities where they shared physical contact, such as physiotherapy. Hewett (2007) discusses the importance of physical contact for social, not institutional, purposes for people with severe intellectual disabilities. This is also acknowledged in Forester and Iacono's work (2008). Hewett acknowledges that certain care based activities that need to be completed should be done sensitively and playful physical contact should be worked into the clinical activities associated with care work, such as supporting people to clean and get dressed. This suggests one of the contributing factors to successful interactions in high rapport pairings (see McLaughlin & Carr, 2005) could be that the person with intellectual disabilities enjoys physical contact from people with whom they have a strong interpersonal relationship.

9.4.2.4 Preference for more communicative service users. Luke described Jenny's relatively good communicative abilities as one of the reasons for their strong relationship. This suggests that more able service users may build stronger relationships with care staff. This is in line with Bowlby's (1969) model where relationships are built by receiving positive feedback on your own actions. It does however raise questions relating to interpersonal relationships and interactions in general for those who lack the ability to provide positive feedback to care staff. Luke expressed difficulties relating to those who do not acknowledge his presence. Perhaps certain approaches or interventions such as Intensive Interaction (Nind & Hewett, 2001) should be central to building relationships with those who are particularly hard to "reach", providing a space where all behaviours are treated as communicative to help overcome such challenges and address this potential bias in services provided to people with severe-profound learning disabilities.

9.4.3 Limitations and suggestions for future research.

9.4.3.1 PIR. The use of partial interval recording allowed Jenny's behaviours to be quantified and enabled the measurement of differences between the behaviours she exhibits when Luke is at varying proximities and at different levels of visibility. However, partial interval recording does not capture the sequential aspects of an interaction. It may be, for example, that the way in which Luke interacts with Jenny contributes to her

changed behaviour, but partial interval recording does not let us tease apart how Luke and Jenny's actions relate to each other. Using this method means neglecting a great deal of richness from the interaction but it does permit a relatively objective method to examine Jenny's behaviours.

Behaviours were coded every 5 seconds and a record made in a binary manner whether behaviours were exhibited in that 5 seconds of video. Timing behaviours would have been a more precise measurement but may have created difficulty in deciding exactly when behaviours start and stop. However, timing vocalisations of particular pitch precisely is possible, and likely to become easier with advances in audio software and would make an interesting focus for future research.

A limitation of the video footage that was examined was that it was not always possible to discern whether Luke was visible to Jenny or not. In addition, some staff members did not consent to being filmed and so it was often not possible to capture the interactions of the whole room. Such data would allow for a richer analysis

9.4.3.2. IPA. Steps were taken to try to ensure that questions were not leading and IPA interview guidelines were followed (Reid, Flowers & Larkin, 2003). However, it is likely that Luke's responses would have been subject to interviewer bias. Additionally, completing the interviews at the day centre where Luke works may have reinforced a perceived need for Luke to present himself in line with the centre's ethos and values.   It may be more effective to explore the negative aspects of close interpersonal relationships between people with severe to profound intellectual disabilities and care staff using a research design that provides greater anonymity and can be completed in a more neutral setting.

Other limitations include that only two interviews were completed and only one person interviewed. However, it would have been inappropriate to include other staff members from the day centre as there did not seem to be another service user – staff member pair where their relationship was especially close though it should be noted that there is no suggestion that there were no other staff members who were skilled communicators within the team.

There are also particular limitations related to specific themes. For example, research has demonstrated that there is a particular type of discourse that surrounds choice in health and care services (Nordgren, 2010; Antaki, Finlay and Walton, 2009). The

emphasis placed on choice in this discourse does not necessarily mean that choice is always being appropriately offered in practice. This puts into question Luke's appreciation of Jenny's rights as a theme. Additionally, other research has demonstrated that communication methods used by care staff differ from the communication methods which they report using (Healy & Noonan Walsh, 2007). Future research could aim to use conversation analysis techniques to note whether any beliefs about Jenny's rights are embodied in interactions.

Finally, a limitation of research using case studies is that it is not possible to generalize from the research. However, this case study instead provides an insight to the subjective experiences of those involved in close staff-service user interpersonal relationships.

9.4.4 Practical implications. It is hoped that this research will spark a discussion about how close interpersonal relationships do exist between care staff and service users. Acceptance of these relationships and further research on the topic would allow guidelines to be established about appropriate interpersonal relationships between staff and service users. Doing this is essential to ensure people with severe to profound intellectual disabilities are suitably safeguarded, but it may also relieve some of the conflict experienced by care staff between having a close interpersonal bond with another and wanting to act within, and be seen to act within, professional boundaries.

Part 2 - CA Comparative Study

9.5 Method

The findings from the partial interval recording demonstrated that Jenny spent more time vocalising when Luke was close and visible than when he was not. Staff comments demonstrated that they interpreted Jenny's behaviours as reflecting a close interpersonal relationship with Luke and his representation of this is described in the IPA section of analysis.

However, Jenny cannot comment about her experience of the relationship. Her emotions are inferred. The use of partial interval recording allowed Jenny's behaviours to be quantified and enabled the measurement of the difference between behaviours which she exhibits when Luke is at varying proximities and at different levels of visibility. It also provided a more objective measure than the subjective beliefs of the researcher, other

staff members and Luke, but it fails to capture the sequential aspects of an interaction. To try to address this issue, below I have examined short sections of four interactions involving Jenny and four different members of staff, one of whom is Luke, using Conversation Analysis.   This analysis focuses upon ways by which Jenny and Luke's relationship is demonstrated through their interactions.   Jenny's seemingly positive behaviours are noted and Luke's turns directed towards Jenny considered. There is also an examination of how Luke's relationship with Jenny is demonstrated in conversation with others.

9.5.1 Selection of video recordings . As the day centre which Jenny attended worked to a timetable of activities, the same support staff and service users regularly completed the same activities together at the same time each week. For example, Jenny would have a physiotherapy session with one member of staff each week, and a gardening session with a different staff member. Because of this, fair comparisons of the interactions of different staff members with Jenny would be difficult. However, the support staff who supported Jenny during lunchtime changed daily. Analysing fragments of the interaction before eating and drinking at lunch time served as a control in several ways. First, such interactions happened in the same place. Jenny always sat in the same position in the centre's dining room for lunch. Lunch always took place at the same time of day. The fragments of video selected for this analysis all involved staff members returning to Jenny, after a period of absence during which they gathered equipment or prepared her food. Four examples and subsequent conversation analysis appear below. There were several incidences of staff leaving the service user to prepare for the upcoming meal in some way in my dataset. These four examples were selected to present here as they all involved Jenny but involved different members of care staff, allowing for some comparisons to be drawn. Some examples have been presented as a number of separate extracts to ensure that the analysis is easily followed. The care staff featuring in these examples are Luke, Leah, Amy and Tom.

9.6 Analysis

9.6.1 Interaction between Jenny and Luke

Figure 16 is the first of three extracts taken from one interaction where Luke is supporting Jenny at lunchtime at the day centre. At the beginning of the extract Luke is not at the table. He is in the dining hall, and soon arrives at the table. Jenny is in her

usual position for lunch which she eats from her wheelchair. I am also sitting at the table.
Although there are several other people in the large dining hall, we are the only people at
the table.

1	Jenny	((sits, looking down slightly with a neutral facial expression for 6.1s, looks
2		up with a neutral expression for 1.8s, then [smiles with a wide open
3		mouth for 24s))
4		[((turning head to her right, eye
5		gaze ahead=))]
6		[AH:HUHhhh[uhhn=
7	Luke	[((c[omes into camera
8		shot on Jenny's right))
9		[◦>one sec Jenny< ◦
10		[((picks up cutlery
11		and begins cutting the food, slightly facing away from Jenny))
12	Jenny	((= hur hur hu:::r huh huh hh. [Hh uh hu
13	Luke	[It's gnocchi (.)◦i've had to chop it up quite a
14		bit for her◦

Figure 16 - Extract 2, Jenny and Luke pre-lunch.

9.6.1.1 Jenny's behaviours and staff interactional availability. Jenny's noticeable
change in her facial expression in line 2 and her head movements and vocalisations in line
6 precede Luke coming into camera shot in line 7. Examples of behaviours such as
smiling, laughing and using a high pitch have been identified elsewhere as serving as
positive emotional displays in the typically developed population (Ruusuvuori & Peräkylä,
2009). It appears that Jenny's change in behaviours represents a shift in emotion.
Emotions are thought to be triggered by, and belong to, an object and, unlike mood, are
always understood to be about something (Ruusuvuori, 2012). The Oxford English
Dictionary (2016) defines an object as "a person or thing to which a specified action or
feeling is directed" and not simply an item or article. As such, Jenny's apparent shift in
emotion may be due to the presence, or availability, of a particular person. In Extract 2,

Jenny's position at the back of the dining hall means that Luke would have been visible to Jenny as he approached, making it very probable that Jenny's shift in emotional displays, first observable in line 2, is related to his presence. This is further evidenced by her continued vocalisations and wide smile after Luke has reached the table and Luke's response to Jenny in line 9 ◦>one sec Jenny< ◦, which treats her behaviours as if he was the target recipient and cause of emotional change.

After a short interaction (which is transcribed and discussed below - see Figure 18, Extract 4), Luke leaves the table for a short period of time and then returns (transcribed below in Figure 17, Extract 3).

Extract 4 is from the same interaction as Extract 2 so also involved Jenny and Luke in the dining hall of Langley. This time, Luke begins at the table, but leaves immediately and returns a few seconds later.

1	Luke	(◦wont be a minute◦) ((leaves the table))
2	Jenny	((looks up smiling, turns to neutral face, stays neutral for 8s, then a big
3		wide smile [which lasts 30s – beyond the length of this transcript))
4		[AHH: ↑hhh:↓hh.hhuh.hhhuh.hhhuh]
5	Luke	[((off camera Luke is approaching the table from the other side of
6		the large dining hall))]
7		>↑hello ↑jenn:↑y< ((comes back into shot and takes a seat to the right
8		of Jenny moving the apron, tissue and other objects necessary for lunch))
9	Jenny	AHH::.<u>CHCHhhhh</u>huh.huh.huh↑AHH: ↑:: a↑aa::=
10	Luke	((begins to prepare the plate and guard))
11	Jenny	=[((leans her whole body back in her wheelchair, so she is almost standing
12		and then leans her face into Luke's shoulder with an open mouth))]
13		=[heh heh heh ahh::h]

Figure 17 – Extract 3, Luke leaves Jenny and returns.

9.6.1.2 Jenny's behaviours and staff increased availability. Extract 3 shows

further changes in Jenny's emotional displays. In line 2, Jenny's facial expression changes from a smile to a neutral face for 8 seconds, shortly after Luke leaves the table. It is worth noting that most change of emotion literature discusses the presence of an

affective behaviour such as smiling or frowning (e.g. Peräkylä & Ruusuvuori, 2006; Ruusuvuori & Peräkylä, 2009) but rarely discusses the cessation of affective behaviours which result in a neutral expression, as is the case here. Clearly, the cessation of behaviours still marks an emotional change.

Jenny's facial expressions change again in line 3-4 when she smiles widely and vocalises immediately before Luke reappears in shot (in line 5) as Luke is approaching the table. Luke, who had not been able to be fully available because of his care duties (see below), takes a seat for the first time in the interaction and sings a greeting to Jenny in line 7. Jenny's emotional displays become more overt in lines 9 and 11-13, where her vocalisation becomes more high-pitched and she uses her whole body to lean back and move in her wheelchair. She then leans onto Luke's shoulder with her mouth which is open. These "upgraded" emotional displays are likely to be in response to Luke's increased engagement and availability.

9.6.1.3 Physical Humour. Analysing Extract 2 in isolation, it is unclear whether Jenny's apparent shift in emotion is intrinsically linked to Luke's presence or whether it is related to the knowledge of the forthcoming activity they will complete together, namely her having lunch. It is also possible that both contribute to the change in her emotional displays. Whichever is true, in Extract 2, line 7, Luke is currently unable to provide his uninterrupted company or Jenny's lunch, as there are still things he needs to collect and preparation which he needs to complete (such as cutting the food into small pieces and collecting the plate guard). Luke's utterance "°>one sec Jenny< °", in line 9, and his positioning of himself and of Jenny's food, both facing away from Jenny in lines 10 and 11 appear to be designed to signal this 'unreadiness' to Jenny. This is not dissimilar to how other professionals, such as doctors, signal their unavailability to others (Newman, Button & Cairns, 2010). It is also clear that Luke is directing his talk in the latter part of line 13 to the researcher, which is evidenced by his use of the person reference "her", when referring to Jenny. Shortly after this relevant interactional unavailability, Jenny launches a new activity which appears to be a deliberate "naughty act", playfully moving the apron, as can be seen in Extract 4 below.

Humour can be physical. Deliberate "naughty acts" are an example of this (Craik, Lampert & Nelson, 1996). Lerner and Zimmerman (2003) demonstrate how pre-verbal children draw upon their early communicative resources to tease other children using

objects. They note that this is achieved by one child presenting an object to the other as if it was an offer, only to withdraw the object before the other child can take it. Learner and Zimmerman (2003) refer to this as a mock transfer as it appears that the child "offering the object" is beginning an object transfer sequence, but instead is actually using the "offer of the object" to conceal and launch a different course of action, where the object "offer" is withdrawn. They suggest that this tease sequence could be characterised as a practical joke, as the joke is achieved by a completely gesticular course of action.

Learner and Zimmerman's research and other studies involving very young children's communication (e.g. Filipi, 2009; Kidwell & Zimmerman, 2007; Lerner, Zimmerman & Kidwell, 2011) demonstrate that relatively complex social action can be completed non-verbally at an early developmental stage. However, examples of such social action being completed by people with severe intellectual disabilities is considerably more limited. Finlay et al (2008) describe informal games initiated by a member of care staff when interacting with a man with severe intellectual disabilities. They identified a dilemma faced by staff members when the behaviours of the person with intellectual disabilities are not immediately or unambiguously positive about an interaction; do they continue or abandon the activity? In the interaction in Extract 4, Jenny launches a sequence of behaviours in which she appears to be deliberately and playfully naughty, and the staff member, Luke, faces a different dilemma. How does he manage to fulfil his institutional care duties (preparing Jenny's food) whilst responding to Jenny's seemingly playful behaviours?

Figure 18 - Extract 4 is taken from the same lunchtime as extracts 2 and 3. It occurs immediately after extract 2. The beginning of Extract 2 overlaps with the end of Extract 4. Luke is present at the beginning of this extract preparing food at the table, mainly chopping the food.

1   Luke   [((chops Jenny's food facing away from Jenny))]

2   Jenny   [((smiles and rubs hands silently for 2s then looks down to the right and

3   leans down and picks up an unused disposable apron from a nearby

4   chair and pulls it in towards herself then pauses her action and shifts

5   her gaze to look up towards Luke with a neutral expression))]=

6   Luke   ((glances towards Jenny then continues looking towards the plate of

7   food and continues chopping her food)) Oi:

8   Jenny   =[((smiles lifting the apron in front of her face))]=

9   Luke   [Ms Tor↑re] [((continues to chop Jenny's food))]

10   Jenny   [=(pulls the apron over her head and puts it down on her

11   left hand side where it gets caught on her arm, she pulls it off her arm,

12   and back over to her right hand side] then looks up to the right towards

13   Luke, smiling)) (.) err errr ((looks down, moving the apron))

14   Luke   (◦wont be a minute◦) ((leaves the table))

15   Jenny   ((looks up smiling, turns to neutral face, stays neutral for 8s, then a big

16   wide smile[which lasts 30s – beyond the length of this transcript))

17   [AHH: ↑hhh:↓hh.hhuh.hhhuh.hhhuh

18   Luke   >↑hello ↑jenn:↑y< ((comes back into shot and takes a seat to the

19   right of Jenny – moving the apron, tissue and other objects necessary

20   for lunch))

Figure 18 – Extract 4, Jenny and Luke playful pre-lunch

In the example above, in line 2, Jenny begins a sequence of behaviours. She
reaches for an apron and pulls it towards her. In lines 2-5, she pauses her action and
shifts her gaze from downward towards the apron, to upwards towards Luke. Then Luke
responds to Jenny without demonstrating his full attention to her. His head remains
orientated towards the plate of food. He does not alter his head position. He does,
however, playfully utter in lines 7 and 9, "Oi: Ms Tor↑re".   Immediately after the "Oi:",
Jenny smiles (see line 8). She then continues moving the apron and looks up smiling in
both lines 12-13 and line 15. She also vocalises with animation, changing the pitch,
seemingly excited in line 17.   Her smiling and vocalisations within this interaction fit into
a cultural pattern of playfulness, and may demonstrate that this interaction is non-serious

(Schegloff, 2001). Jenny's looking up in lines 4-5 suggests her behaviours are designed for an audience. It appears she is being playfully "naughty" which is supported by Luke's response in line 7, where he uses the word "Oi:". In English, "Oi" is a colloquial interjection used to "attract attention. Also used to express objection or annoyance" (Oxford English Dictionary, 2016). A serious use of the word "Oi" here would probably reflect genuine objection or annoyance, but Luke follows it up with her full name with a change in pitch, perhaps suggesting that he too is joking (Purandare & Litman, 2006; Flamson, Bryant & Clark Barrett, 2013). Sandlund (2004) offers examples of how "mock emotions" are displayed in interactions between lecturers and students and are used as a resource for playfulness. Sandlund presents instances of how people achieve mock surprise, mock annoyance and resignation, mock horror/being appalled and mock remorse. Mock displays of emotion draw from shared cultural understandings of how emotions are usually expressed and responded to (Sandlund, 2004). Here, Luke's response to Jenny in lines 7 and 9, appears to serve as "mock annoyance" or a "mock telling off" to which Jenny responds positively, smiling, and continues moving the apron. Luke manages the competing tasks of interacting with Jenny and preparing her lunch by providing a verbal response to Jenny's deliberate "naughty act" while signalling non-verbally that he is largely unavailable. While Luke provides Jenny's behaviours with a response in lines 7 and 9, which appears to align with the playful tone of the interaction, he does not fully engage with the course of action Jenny has launched, which involves playing with the apron. He remains largely focused on the food.

Her behaviours change, however, after Luke leaves the table in line 14, when her facial expression returns to neutral until Luke is visible again in lines 15-16.

9.6.2 Interaction between Jenny and Leah. Leah is a member of care staff who regularly works closely with Jenny. She speaks Jenny's mother tongue and is the person at the centre who communicates with her family. When Jenny and Leah are in the dining room, several other people are also there. These include service users with mild-moderate intellectual disabilities, including Jason who talks in this extract. At the beginning of this example, Leah is standing to the left of Jenny's wheelchair making preparations for the upcoming meal including taking various food containers out of a larger box.

1   Jenny   [(((looks towards Leah with a neutral face))

2   Leah   [((moves about containers which hold Jenny's lunch))

3   CN   [(((laughs with someone who is off camera))

4   Leah   I'[¹M [²TOO]¹ ↑BU↓SY ((animated voice)) (speaks in Portu]²gese   ) I

5   can't feed everybody ((moves out of camershot))

6   Jason   [¹↓al[right=]

7   Jenny: [²((smiles broadly looking to her right, seemingly towards Andrew))]

8   ((without changing her gaze, her expression changes to neutral))

9   ((looks around with a neutral face for 13.6s))

10   ((brief smile))

11   ((8s -looks around, neutral face))

12   ((brief smile, stretches right arm outwards slightly))

13   ((15s – looks around, neutral face))=

14 Leah   Sorry Jenny , I >have to= ((returns to camerashot))= heat this [first<

15   because it's erm (3.9) was in the fr:idge

16   [((opens

17   containers and takes food out))]

18 Jenny   [=((looks

19   straight ahead towards Leah's face then looks at the food/Leah's hands ,

20   leans slightly forward, still looking and then right then looks up and back

21   again then looks slightly to her left then to food/hand -with a neutral facial

22   expression throughout))]

23 Leah   (leaves))

24 Jenny   ((tracks Leah moving around the room, off camera, with her eye gaze))

Figure 19 – Extract 5, Jenny and Leah pre-lunch

   9.6.2.1 *Jenny's behaviours and staff interactional availability.* In Extract 5, Jenny
demonstrates that she is regularly attending to Leah. For example, she clearly attends to
Leah's actions from lines 19-20. Jenny also tracks Leah's movements around the room in
line 24.   Jenny does not, however, show the same patterns of behaviours in response to

Leah's arrival and departure as she does when Luke arrives and leaves. For example, when Leah re-arrives in line 14, Jenny's facial expression stays neutral. The brief smiles at lines 11 and 13 appear to be because she has seen people off camera, but unfortunately we do not know who she has seen, as this was not recorded and Jenny eats lunch in a large dining hall which holds several people. Jenny's smile in line 7 is slightly ambiguous; it is possible that her smile was a response to Leah's animated speech in line 4. However, in the video, it looks much more likely that Jenny's smile is a response to the greeting from Jason, a service user, in line 6. Jenny's gaze seems beyond Leah's position, and her eye gaze is towards where Jason usually sits.

9.6.3 Interaction between Jenny and Tom. Tom is a relatively new member of care staff and has been at this centre for approximately 2 months on a part time basis. The following extract is taken from the start of a video where Tom is approaching the table after leaving the room briefly. Jenny and I are already sitting at the table, Jenny in her wheelchair.

1	Jenny	((sits looking behind her wheelchair, towards a window with a
2		neutral expression for 1s))
3	Tom	((approaches the table with an empty plate and food in containers in
4		his hands, [and walks behind Jenny's wheelchair, into her view))]
5	Jenny	[((tracks Tom's movement, looking towards the plate and
6		containers in his hands))
7	Tom	[(((comes over the table, stands to the left of Jenny] [moving
8		containers of food))
9	Jenny	[(((continues to look at the plate and Tom's hands))]
10	Tom:	[(∘I'm just gonna
11		plate[up (.) thi:s∘)
12	Jenny:	[(((looks up with an open mouthed smile towards Tom 1.8s))
13		((back to neutral face, rubs hands))
14	Tom:	j- I'm just gonna [prepare ya <u>lunch:</u> for ya JENny
15	Jenny:	[(((smiles broadly for 5s rubs hands))=
16	Tom:	<u>W::</u>o:w ((starts scooping food onto the plate))

17	Jenny:	Mm
18		=((neutral face, stares ahead then to Tom's hands which are scooping
19		food from a container onto the plate))
20	Tom:	((finishes transferring the food and bangs the cutlery on the plate))
21	Jenny:	((looks up towards Tom, opens then shuts mouth; holds and rubs
22		hands))
23	Tom	[((cuts the food – 19s))]
24	Jenny	[((looks back at the hands/food with a neutral expression))]
25	Tom:	((looks at the camera)) .h
26		(2.0)
27		[((looks towards Jenny and bends slightly)) <GOT RAVIOLI WITH
28		SAUCE today>]
29	Jenny:	[((neutral face))]
30	Tom:	((continues to chop food for 4s))
31	Jenny:	((slight smile)) (.) ((open mouthed smile looking up at Tom– 1s))
32		((rubs hands))

Figure 20 – Extract 6: Jenny and Tom pre-lunch

9.6.3.1 Jenny's behaviours and staff interactional availability. In extract 6 Jenny shows positive emotional displays in lines 12 and 15. These overlap with Tom's first two utterances in lines 10-11 and 14, suggesting that Jenny's positive behaviours are related to the interactional, not physical, availability of the staff member. Although Jenny clearly was attending to Tom (and/or the food) as he approached the table (lines 5-6), she did not exhibit any overtly positive emotional displays until Tom spoke (see lines 10-15). It could be argued that Jenny is excited by the content of Tom's talk, which implies that Jenny's food will soon be ready. However, similar meaning could be inferred by Tom bringing the food and a plate to the table, in line 3, which Jenny responded to minimally, only changing her eye gaze, perhaps making it more likely her response is actually to the increase of Tom's interactional availability.

These emotional displays, although positive, differ from the emotional displays which feature in the interactions in Extracts 2, 3 and 4 with Luke. Her smiles are not as

wide and they last for shorter periods of time. She does not lean back in her chair to stretch her whole body and there are no vocalisations within this section. In contrast, a range of vocalisations, including a high pitched, squealing, seemingly excited, vocalisation, occur in the extracts involving Luke.

*9.6.3.2. Experience and epistemics .*Tom's behaviour from lines 25-28 may mark his awareness of being filmed. He looks at the camera directly before an audible in-breath in line 25 which may suggest he is preparing to talk. However, this is followed with a two second silence. Then, the utterance he does produce is louder and slower than his regular talk potentially demonstrating a particular effort to engage Jenny. It appears as if he felt the need to break the silence but was unsure of what to say. This may reflect his relevant inexperience, as a new member of staff, working with Jenny. Seconds after this, Luke comes over to the table as can be seen in Extract 7.

Extract 7 happens within the same lunchtime as extract , so it also details interactions from a lunchtime where Tom is supporting Jenny. Although Luke has no official duty to support Jenny here, he comes to assist near the beginning of this example. Jenny is at her normal table in the dining hall but not in her usual position at it. This interaction allows an examination of how Luke demonstrates his closeness to Jenny through his conduct, both with Jenny herself and other supporting staff members.

1	Jenny	((looks towards Luke with a large open mouthed smile)) err ((puts
2		head back and up to continue to look at Luke))
3	Luke	((arrives with an apron obscuring the cameras view of Jenny's face))
4		here you go ((gestures with the apron)) right ere ar
5	Jenny	[((looks up at Luke smiling))]
6	Luke	[((puts the apron over Jenny's head))]
7		[((Luke & Jenny continue to put the apron on))
8		((Jenny puts her arms in the air and Luke ties the apron ends, then he
9		ruffles the bottom of the apron while she smiles))
10	Jenny	Grhm
11	Tom	[is that the right PUDding? It's the o:nly one I could fi::nd .in the
12	Luke	fridge
13		◦yea (.) that's one of Jenny's◦
14	Tom	(◦she seems to love them, that's like a national dish◦)
15	Luke	Isit? Yea
16	Jenny	that's her national dessert!
17		Huh huh huh
18		(inaudible as Luke and Tom swap places as Tom leaves to go to the
19	Luke	microwave and Luke continues with Jenny's apron)
20		she NEEDS to sit over in THIS position (puts arm out straight across
21	Tom	himself)
22	Luke	(2.5) on that side (.) there?
		Yea (.)I'll move her though (.) it'll be alright

Figure 21 – Extract 7, Jenny and Tom with Luke, pre-lunch.

9.6.3.3 Relationship demonstrated through Epistemics. Extract 7

demonstrates the epistemic difference in both status and stance between Luke and Tom.

Luke has more knowledge about Jenny than Tom and they both demonstrate this through

their talk and actions (Heritage, 2010). This is evidenced by the very action of Luke

coming over to the table to support Jenny with her apron even though it is Tom who is

supporting her during lunch. Furthermore, Tom asks Luke for confirmation about how to

support Jenny correctly during the interaction. For example, in line 11 Tom asks for

advice about whether he has picked the right dessert (which he had) and Luke provides him with an affirmative answer in line 12. This demonstrates that Luke knows additional information about Jenny that is not otherwise available to Tom, underlining Luke's closer relationship with Jenny. Luke adds an additional comment in line 13 about Jenny's opinion of that dessert. Here, however, his epistemic stance is reduced, stating that ∘she seems to love them∘. The use of "seems to" in this sentence, appears to be representing an acknowledgement of this reduced epistemic status. In other words, he might think he knows Jenny well but still accepts that her inner thoughts cannot be unambiguously interpreted. Luke then offers knowledge which he does have, namely how the dessert relates to her culture. Tom takes a low epistemic stance on this, treating it as new information. Tom has family who live in Jenny's home country and he had recently been on holiday to a neighbouring country. It is possible that Tom did not know about this particular dessert and its relevance to Jenny and her family's culture but it is also possible that he adopted a less knowledgeable stance as is preferred when there is a more knowledgeable speaker (Clayman &Heritage, 2014). Tom and Luke appear, perhaps, to have somewhat taken on the roles of student and teacher (McHoul & Luke, 1989). Having knowledge about a person relates to knowing them a long time and having a good relationship with them (Forester & Iacono, 2008; Martin et al., 2010).

9.6.4 Interaction between Jenny and Amy. In Extract 8, Amy is supporting Jenny with her lunch. Jenny is at her normal position within the dining hall and Amy has left to prepare Jenny's lunch.   This involved collecting and heating food and collecting cutlery. At the beginning of the extract Jenny is sitting at the table with CN (the researcher). Luke also features in this extract.

1	Jenny	((rubbing hands looks around the room with slight smiles at times,
2		occasionally looking to the floor, eye gaze appears to be following
3		people off camera around the room for 21s – then briefly looks at
4		camera/researcher))
5	CN	°It's you if that's alright°
6	Jenny	((smiles slightly, looking at CN 1.5s, then continues rubbing hands and
7		looking around the room for 6s))
8		((mouth opens wide, closes, then opens wide to a [broad smile, still
9		rubbing hands))
10		. [er↑rr:::;r↓r::
11	Luke	((voice can be heard although speech inaudible talking to other service
12		users off camera))
13	Jenny	((still smiling she looks up and her face returns to neutral – 4s))
14		((bangs on the table lightly looking at her hand))
15		((looks up after 2s and moves her head seemingly following Luke's
16		movements off camera, she smiles with a [broad open smile – 22s))
17		.hhh urr::rrrr=
18	Luke	[((arrives [in shot to the right
19		of Jenny holding an apron out in front of him, then walks around the
20		back of Jenny's chair to her left hand side – off camera))
21	Jenny	=[((follows [L with her eyes,
22		and moves her head to face him as he changes position, still smiling
23		broadly))
24	Amy:	((out of camera shot but walking nearby the table on Jenny's right))
25		[It's a VERY LARGE portion
26	Jenny	Ahh (.) ah[h ((leans back in chair, still broadly smiling, looking at Luke to
27		her left, leaning towards him))
28	Luke	[>yea< don't give her all of it ((continues sorting the apron
29		throughout moving around to behind Jenny until the end of the
30		extract))
31	Jenny	[↑Err (.)[er↑rr (.) errr]

32		[((large broad smile looking towards Luke))]=
33	Amy	[It's HU:GE
34	Jenny	[↑Heh heh hh: heh]
35		=[((continues to look and widely smile towards Luke))]
36	Amy	[((comes into shot on the right hand side on Jenny and puts the plate
37		and tupperware on the table, looks at plate and then towards the
38		researcher/camera)) it came out in <u>one lump!</u>]
39	Jenny	((looks towards Amy)) Errr ((leans forward and taps Amy 3 times on the
40		lower back during which her facial expression returns to neutral))
41	Amy	[It's HUGE jenny=
42	Jenny	[((spoons some of the food back into the tupperware))]
43		=((broad smile for 2s looking towards Amy))

Figure 22 – Extract 8, Jenny and Amy with Luke pre-lunch

9.6.4.1 Jenny's behaviours and staff and researcher interactional availability. In Extract 8 Jenny once again shows increased positive emotional displays as the interactional availability of the people around her increases. The first example of this in Extract 8 is in line 6 after the researcher verbally responds to Jenny's eye gaze, explaining that the purpose of the camera in this session is to film her by uttering °It's you if that's alright°. Although Jenny's smile which follows this could be interpreted as her consent/assent to being filmed, the purpose of the researcher's conversational turn was not to gain consent from Jenny (MCA guidelines had already been followed) nor did the researcher interpret Jenny's response to be addressing this issue. Instead, the researcher was aiming to provide a response to Jenny's behaviours regardless of whether Jenny's behaviours were meaningful or not. Assuming intention is a principle discussed and encouraged in many handbooks relating to interacting with people with severe intellectual disabilities (Caldwell, 2005, 2006, 2008; Nind & Hewett, 2001, 2012) and one I somewhat adopted to help guide my own behaviours. There is, of course, a possibility, that Jenny can understand what the researcher is saying, in which case this exchange could have provided Jenny with the opportunity to express an immediate preference (these issues are discussed in chapter 8,Vulnerability). However, considering her disabilities, it is more likely that her (mildly) positive emotional display is due to the

increased availability of the researcher, who despite being sat at the table had not yet interacted with Jenny until this point. Because of the purpose of the research and Jenny's relatively subdued response, the researcher does not then attempt to extend the interaction and neither does Jenny, who then displays more neutral behaviours following this short exchange.

As with other extracts, Jenny's responses are considerably more pronounced when Luke arrives in line 18 her broad open smile (first seen in line 16, moments before Luke arrives at the table) lasts for over 20 seconds and she makes vocalisations, which are high-pitched and occasionally sound a little like panting or laughing, and are heard to be excited/happy throughout this period. Her eye gaze and head position towards Luke further demonstrate that he is the cause of her emotional shift. She also leans towards him and leans back in her wheelchair.

However, as can be seen towards the end of the extract, Jenny does still attend to Amy even as Luke is finishing sorting the apron behind her. She taps Amy three times and smiles broadly after Amy uses her name. She does not, however, respond to Amy's speech when she is otherwise engaged with Luke (in line 26), even when Amy's speech is loud and emphasised. Additionally, Jenny does not lean back in her wheelchair or produce high pitched vocalisations at the points where Amy's interactional availability increases which it does so verbally in line 25 and physically in line 24.   On the other hand, Luke's increased interactional availability appears to elicit these responses.

9.6.4.2. Experience and epistemics. Although it is Amy who is supporting Jenny throughout lunch, it is again Luke who comes over to put Jenny's apron on. Regardless of whether, or how, it was arranged that Luke would provide this support to Jenny, the fact that he did offer support to both Amy and Tom in the extracts within this section and at other times, highlights his closeness with Jenny. Although Amy is an experienced member of care staff, she had only been working in this service for a matter of months.

Luke's epistemic advantage, relating to supporting Jenny, is demonstrated, as it is in the extract involving Tom, by Luke's knowledge about her food. In line 25, Amy comments about the size of Jenny's portion, to which Luke replies >yea< don't give her all of it, demonstrating his knowledge about Jenny's eating habits.

9.7 Discussion

An examination of the first few minutes of video of Jenny's lunchtime sessions allowed for comparisons to be drawn. Similarities and differences between the examples in this section can be identified. On many occasions, Jenny demonstrated positive emotional displays which increased with staff/researcher interactional availability. In these interactions the behavioural/conversational turns followed a similar pattern. However, the actions which constitute each turn vary.   Regularly the sequence of behaviours could be described as the base adjacency pair outlined below:

FFP: Demonstration of increased staff interactional availability

SPP: Increased positive behaviours exhibited by Jenny

One noticeable aspect of these extracts is that Luke appears in several, even when he has no formal responsibility. The very fact that Luke features in three of the four examples, even when it is the responsibility of another member of staff to support Jenny during her lunch, demonstrates that he has frequent interaction with Jenny beyond those that are institutionally prescribed. Luke providing additional support to Jenny does not feature in Jenny's eating and drinking care plan nor on the whiteboard detailing staff responsibilities for the day. If Luke's additional support has been arranged, it is on an informal basis. On the occasions when Luke did help, he did so by bringing and supporting Jenny into an apron and by offering care staff who know Jenny less well advice about supporting her during mealtimes. He may choose to complete these activities to model good practice and to encourage and teach care staff less experienced in supporting Jenny.

The behaviours which Jenny exhibits are a clear demonstration of her preference for Luke's company. Her positive displays are considerably more overt in response to him than to other members of staff. Some behaviours, such as leaning her whole body into her wheelchair, appearing similar to a squirm or outpouring of pleasure, and particularly high pitched lengthy vocalisations appear to be reserved for interactions with him. She also leans closer and onto Luke, something that is considerably less common with other members of staff.   In all of the extracts in this section Jenny does not display uncooperative behaviour. This is typical of the observations made throughout the research project. In fact, she regularly exhibits positive displays even when interacting

with staff other than Luke. It is the extent and strength of Jenny's positive actions which mark her relationship with Luke as special.

However it is not only Jenny's behaviours which demonstrate that her relationship with Luke is special. Luke demonstrates his knowledge about Jenny through his talk. His epistemic stance and status are high. He provides assistance and knowledge to other members of staff (for example in extract 7), even those with several years of care experience. In contrast to Luke, the epistemic stance of other care staff is low. From evidence in this chapter, which is consistent with observations throughout the research, it is clear that Luke is a valuable resource for both Jenny and other staff members. At times, he acts as an advocate for Jenny and at other times a teacher for his colleagues. However, a note of caution should be struck. As Goode (1994) notes, some care staff may build relationships with service users with intellectual disabilities which appear to exhibit qualities of ownership.   He suggests that some relationships be characterised as "pet owner-pet" (p.157) by providing treats and special treatment but without due respect. However, relationships where one partner has more control, also exist within the non-disabled population.   From reading Goode's work (1994) and my own experience in this research (and otherwise) I suggest that staff members having an increased epistemic status relating to a service user may be a contributing factor in the development of ownership in relationships. It is imperative to note, however, that the relationship between Jenny and Luke did not appear to be characterised as the "pet owner – pet" type relationship that Goode described. Whilst clearly caring for her, Luke made obvious efforts to enhance Jenny's independence.

It was noticeable in Extracts 3, 6 and 7 that Jenny appeared to respond positively to animated and expressive speech. In particular she displayed positive emotions after staff members addressed her using a voice which could be described as using motherese. Motherese, or infant directed speech, is a particular type of talk which parents use to speak to babies or young infants (Grieser & Kuhl, 1988). Jenny appeared particularly responsive to speech which varied in pitch, like a melody. Nind and Hewett (2001, 2012) suggest that such patterns of speech should be used when interacting with people with severe intellectual disabilities. However, as Wolfensberger (2000) outlines, there are concerns about treating adults with intellectual disabilities as children. Such concerns may relate to decreased independence and respect. However, using approaches that are

informed by parent-child interactions (such as Intensive Interaction see Chapter 2) may be useful for practitioners., These extracts support that the use of animated speech, similar to motherese, may be a useful tool when interacting with some people with severe intellectual disabilities. However, as this chapter has presented a casestudy it would be important to explore how other people with severe intellectual disabilities respond to such speech before any conclusions could be drawn. It is also likely that conversation analysis research which examines how pre-verbal children use their communicative resources, such as gaze, pointing and vocalisations (Kidwell, 2014; Filipi, 2009; Kidwell & Zimmerman, 2007); could be useful starting points when considering the interactive resources available to people with severe intellectual disabilities.

One further point of note taken from Jenny's interaction with Luke is Jenny's ability to be playful and initiate a new activity which has the ability to influence the trajectory of the interaction. Often interactions involving people with severe intellectual disabilities are directed by the non-disabled person within the interaction (e.g. Bunning et al., 2013; McConkey, Morris & Purcell, 1999). Furthermore, interactions between typically developed people are often not goal oriented. As Finlay et al (2008) acknowledge, people often spend time joking, gossiping, bantering and 'chewing the fat'. Spending enjoyable time communicating with another is an end in itself. Such values are mirrored in several approaches relating to interacting with people with severe intellectual disabilities (e.g. Nind & Hewett, 2001; 2012; Caldwell, 2005, 2006, 2008). However, such approaches often entail the allocation of time specifically to this activity (sharing time and space with another). In Extract 4, Jenny demonstrates her capacity to initiate a playful course of action herself. Although playful interactions or "games" between people with severe intellectual disabilities and care staff have been analysed elsewhere (Finlay et al., 2008) those interactions were initiated by staff members. Because of this, in the examples that Finlay et al. describe the staff are interactionally available. By contrast, Luke has immediate institutional and care responsibilities and Jenny's playfulness, although responded to, is not fully encouraged. Please note that although in this instance Luke did not fully respond to Jenny's playful behaviours, there were several other examples across various activities where Luke did respond to Jenny's playful initiations.

9.7.1. Jenny's decision making abilities As outlined in chapters 2 and 7, the DSM-5 (APA, 2013) suggests that people with severe intellectual disabilities do not have the

capability to make and express decisions relating to their well-being. However, it appears that Jenny is happier when around Luke and clearly expresses that by the marked, and particular, increase in her positive behaviours. The question "who would you like to spend time with?" is an important decision for everybody, including those with severe intellectual disabilities.   Even if Jenny's increased positive behaviours were not intentional she can still demonstrate a clear preference in support staff.   These decision making capabilities should be fully acknowledged both in the lives of people with severe intellectual disabilities and in the publications which help diagnose their disabilities.

9.7.2. Recommendations for practice. From the observations made in this section and the related ethnographic notes which were made throughout the research project I would make the following recommendations for practice.

First, recent research has begun to address the fact that close relationships do exist between service users and staff members (Forestor & Iacono, 2008). The extracts in this section offer further empirical evidence for this. As far as possible these relationships should be respected and considered when staff-service user pairings are decided upon. However, such relationships may increase the likelihood of abuse (Franklin, Raws & Smeaton, 2015) or fear of accusation of it (e.g. Forester & Iacono, 2008; Hewett, 2007). Close service user-staff relationships should be acknowledged and discussed, and guidelines relating to appropriate practice set out. Without addressing the fact that close interpersonal relationships exist, the benefits that they provide could be minimised and the safeguarding risks that accompany them increased.

In this chapter I have focused on interactions involving Jenny. It is important to note how her relationship with Luke clearly affects the nature of her interactions. She regularly demonstrates positive emotional behaviours, which although pronounced in her interactions with Luke, are also present in her interactions with others. As already discussed, as staff interactional availability increases, generally so do Jenny's positive behaviours. However, this is not the case for all service users across all interactions. The next chapter, Resistance, examines such interactions.

10. Resistance

10.1 Overview

In the previous chapter , it was shown that Jenny's positive behaviours increased with staff availability and engagement. This was pronounced in response to Luke. This was a trend that could be observed across the extracts. This chapter examines interactions where increased staff availability does not lead to positive, engaging behaviours from the person with severe intellectual disability. Instead, examples of behaviour by service users which demonstrate that they are overtly resisting or where there is a noticeable absence of aligning behaviours, which allow for the activities to be completed, are outlined. Such examples are referred to as resistance. This is in line with Muntigl's (2013) definition of resistance "as a form of non-compliance (e.g. opposition or avoidance)" (p.18).This is a topical area of research as recent government policy relating to people with intellectual disabilities in the UK places an emphasis on people being able to make choices and have control over their own lives. This rhetoric can be seen in both *Valuing People* (Department of Heath, 2001) and *Valuing People Now* (Department of Health, 2009) and within the more recent paper *No Voice Unheard, No Right Ignored* (Department of Health, 2014). Such policies outline principles and objectives to which we, as a society, should strive to adhere. However, they lack detail about how to do so in practice.

Also, as Antaki et al. (2009) note, policies relating to choice and control for people with intellectual disabilities tend to refer to big, fundamental life choices. For example the main topics in *No Voice Unheard, No Right Ignored* are concerned with issues such as where to live and who has control of finances. However, the smaller, more frequent everyday decisions, such as who to sit next to in a room, what to eat, and which activities to take part in, are overlooked.

Ideally, people with intellectual disabilities would be able to demonstrate their choices unambiguously and would be able to initiate new activities without difficulty. However, this is unlikely to be the case for people with severe intellectual disabilities. By definition, people with severe intellectual disabilities need support with many everyday tasks and have limited symbolic communication abilities (APA, 2013). There has, however, been a relatively recent body of literature (e.g. Nind and Hewett, 2001; 2012,

Ware, 2003) which encourages communication partners to allow people with intellectual disabilities to initiate and lead interactions. As outlined in Chapter 2, approaches such as intensive interaction increase the number of initiations by people with severe intellectual disabilities (Anderson et al., 2008; Samuel, Nind, Volans & Scriven, 2008). Antaki et al., (2017) also provide a fine-grain examination of naturally occurring everyday interactions in which people with severe intellectual disabilities initiate a course of action.

Whilst this research and the move towards promoting initiations made by people with intellectual disabilities is encouraging, research suggests that non-disabled communication partners still tend to make more initiations than people with severe intellectual disabilities (e.g. Bunning et al., 2013). It has also been suggested that attempts made by people with severe intellectual disabilities to initiate an interaction largely fail (Antaki et al., 2017). This may reflect inequalities in terms of power and control but may also capture differences in communication repertoires of the people in the interaction. With limited communication resources, it may be considerably more difficult for people with severe intellectual disabilities to launch an activity unambiguously. Many centres providing care also employ, either formally or informally, a practice called "active support" (see Mansell and Beadle-Brown for an overview, 2012) to ensure that even if a person is unable to initiate an interaction independently, they are encouraged and supported to be active, physically and socially. For further details on active support please see Chapter 2.

As such practices are increasingly employed, it is important to recognise that there may be situations when promoting a certain trajectory of interaction may be unwise or unkind. As Finlay et al. (2008) acknowledge, staff members (amongst others) need to decide when it is appropriate to pursue an activity and when it is better abandoned. Various guidelines (e.g. Nind & Hewitt, 2001; 2012; Ware 2003) which advise on interacting with people with severe intellectual disabilities acknowledge that communication partners should stop an activity when a person with severe intellectual disabilities disengages from it. However little attention has been paid to the way in which people with severe intellectual disabilities may demonstrate their disengagement from, or resistance to, an activity. There are some exceptions to this. Finlay, Antaki and Walton (2008) examined how people with severe intellectual disabilities resisted being weighed and how care staff responded to these refusals. Turning and moving away from the

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weighing scales were two of the resistance strategies used. They also detail one person seemingly start another activity to avoid being weighed. However, despite clear refusal strategies, staff regularly still encouraged the service users to be weighed. Further research by Finlay et al. (2008) describes two situations where it is ambiguous whether a person with severe intellectual disabilities is engaging with informal games initiated by care staff.

This chapter aims to address how a person with severe intellectual disabilities resists and/or does not engage in an activity and the ways they communicate that with limited communicative resources. It attempts to outline and examine the actions of people with severe intellectual disabilities and care staff members across a number of episodes in which people with severe intellectual disabilities resist particular activities. Before this analysis is presented, the related intellectual disability and conversation analysis literature is summarised.

10.1.1 Intellectual disability research. As Wehmeyer and Field (2007) note, for a person to act in a self-determined manner it is not only necessary that they initiate activities, they also need to communicate to others when they do not want to participate in an activity. Brown and Brown (2009) outline four areas of choice making: 1. the freedom and opportunity to make choices, 2. familiarity with choice options and activities, 3. demonstrating initiative to make choices and 4. the development of skills and methods a person can use to demonstrate their choices (Brown & Brown, 2009).

A recent overview entitled "Choice Making and Individuals with Significant Disabilities" by Wolf and Joannou (accessed 2017) has outlined both the benefits of, and barriers to, choice making. The authors report that barriers include that there are few opportunities for choice making; the urgency of certain decisions; an adherence to rules and procedures; and the lack of proper training relating to choice-making. The latter is required because, as Antaki, Finlay, Sheridan, Jingree and Walton (2006)] demonstrate, when people with intellectual disabilities are attempting to make a choice, limited communication skills mean that they need assistance from others to be able to express fully their choice. This does not always happen. Previous studies looking at more direct complaints made by people with intellectual disabilities within care services have found that they can sometimes be resisted or reformulated by staff (Antaki et al., 2002; Jingree et al., 2006). Through applying discourse analysis to interview data, Jingree and Finlay

(2013) suggest that it may take some discursive skill for those with intellectual disabilities to design their complaints in such a way that they are taken seriously. The participants with severe intellectual disabilities in my research are not able to communicate verbally which in turn poses the question: how then, are they able to resist an activity they do not want to participate in? The use of a conversation analytic approach to examine interactions where staff treat service users' behaviours as resistance may begin to address this.

10.1.2 CA research. For a general overview of CA methodology and its use in analysing interactions involving people with limited communicative resources, such as people with intellectual and/or communicative difficulties (please see Chapters 1 and 6). Below, the conversation analytic principles and research specifically relating to this chapter are briefly outlined.

Within conversation, there are two types of agenda. There is a topical agenda, which is what the talk or behaviour *is*, and there is an action agenda, which is what the talk *does* (Hayano, 2012). When a person resists an action agenda of another speaker in conversation, often the topical agenda is maintained. People may resist the course of action which the talk is designed to achieve whilst still maintaining the topic of the talk. Heritage (2003), see Figure 23 below, offers the example of Edward Heath, a British politician, being interviewed by a news reporter and asked about whether he liked Harold Wilson, a political opponent. Whilst Heath does not answer the question, he also does not entirely change topic. He resists the action agenda, avoiding discussing whether or not he likes Wilson, whilst attending to the topical agenda, keeping the talk about Wilson.

```
(5) Heritage (2003a: 67)
1    IR:    Do you quite li:ke him?
2           (.)
3    IE:    .hhh .h .h We:ll I th-I think in politics you see:
4           i- ts not a ques:tion of going about (.) li:king
5           people or not, hh It's a question of dealing with
6           people, °°h .h°° a:n::d u::h (.) I've always been
7           able to deal perfectly well with Mister Wilson,=as
8           indeed: uh- he has with me,
9           (0.4)
10   IR:    <But do you like> him?
11          (.)
12   IE:    .hhhh Well agai:n it's not a question of uh (.)
13          li:kes or disli:kes. I::t's a question of wor:king
14          together:: with other people who are in politics,
15          (0.6)
16   IR:    But do y'like him.
17          (0.4)
18   IE:    .hhh (.) That'll have to remain t'be see::n won't
19          it.
```

Figure 23 – Heritage's example (2003) of agendas in talk, cited and taken from Hayano (2012, p.402).

It is worth noting that although much of the conversation analysis research which examines resistance often discusses it in relation to a recipient's design of an answer in response to a question, (e.g. Heritage, 2003; Hayano, 2012) this is not always the case (e.g. Mandelbaum, 1991, Vevhilanin, 2008).

Conversation analysts have studied how people show resistance in a variety of settings. For example, Heritage (2003) provided examples of how politicians resist interviewers' action agendas in news interviews, Mandelbaum (1991) details different ways in which recipients resist the complaining action a storytelling is designed to achieve, and Vehvilainen (2008) outlines student resistance to academic supervision. Other data has come from workplaces (Heath, 1986), classrooms (Monzoni, Duncan, Grünewald, & Reuber, 2011), playgrounds (Lytra, 2007), police interviews (Forrester & Ramsden, 2000) and helpline calls (Kitzinger, 2000). Kent (2011) examines resistance, including embodied actions, during family mealtimes.

Examples can also be drawn from clinical populations and/or from healthcare interactions. MacMartin (2008) gives examples of clients resisting questions from psychotherapists which frame the client in a positive light. Vehvilainen (2008) provides examples of patients resisting their doctor's institutional agendas. Other examples of patients resisting a physician's recommendations come from primary adult care (Costello & Roberts, 2001), women giving birth (Jackson, Land & Holmes, 2017), paediatrics (Stivers, 2006;2007), and oncology (Roberts, 1999).

The various ways in which speakers demonstrate resistance verbally include rephrasing questions (Heritage, 2003), changing topic, providing accounts, presenting contrasting ideas and disagreement/denials (Widdicombe, 2017 as cited in Joyce, 2017). While most of the research which has examined resistance has focused on talk, many studies have also noted the non-verbal aspects of resistance, namely the use of silence, either as a non-response or a noticeably delayed response (e.g. Jackson et al., 2017; Kitzinger, 2000; Forrester & Ramsden, 2000; Monzoni, 2011; Lytra, 2007) body movement and posture (e.g. Heath, 1986) such as turning away, and gaze withdrawal (e.g. Kidwell, 2006; Goodwin, 1981; Hoey, 2017). For example, in Kidwell's papers she

discusses young children's resistance to adults' directives (e.g. Kidwell; 2009) by way of averted eye gaze. As the participants in my research with intellectual disabilities do not have access to the communicative repertoire of neuro-typical adults, my analysis of the service users' behaviours also focuses on non-verbal behaviours.

10.2 Method

Alongside the examination of my ethnographic notes, the video data were analysed using a bottom up approach. Close attention was paid to the behaviours which formed the conversational turns. Particular attention was paid to possible signs of resistance by participants with severe intellectual disabilities, and to the sequential organisation of the interactions.

10.2.1 The impracticality of a count. Ideally, a count of the number of instances of a particular behaviour or course of action within an interaction would be provided to demonstrate how regularly it occurs. Unfortunately, it is not practical to do so here. As presented in the analysis below, resistance to an activity can take the form of a long–lasting, overt resistance to an activity or can be a short temporary state. Furthermore, lack of interactive behaviours could be, and are on occasion, believed by professionals to demonstrate resistance. However, such behaviours could also demonstrate an inability to understand what is required of an activity or the inability to complete it. Medications, such as sedatives, could cause a lack of interactive behaviours and therefore disengagement may not always equate to active resistance. It is important to note that although in my research there was variation in the level of resistance shown by the different participants, and indeed staff responses to it, examples of disengagement or resistance were frequent within both the video data and the ethnographic notes.

10.3 Analysis

From the analysis, three main categories of non-engagement or resistance to an activity were identified.

1)   No or minimal engagement with an activity

In these examples the person with severe intellectual disabilities demonstrates little engagement in an activity or interaction initiated by care staff.

2)   Resistance to an activity

In these examples the person with severe intellectual disabilities overtly resists an activity from the start of the initiation by care staff.

3)   Resistance within an activity

In these examples the person with severe intellectual disabilities appears to resist and/or disengage during an activity.

These can occur in isolation or together as part of the overall trajectory of an interaction as exemplified in extracts set out in this chapter.

10.3.1 No or minimal engagement with an activity.

10.3.1.1. Simon in art. During the months while I was filming, Simon frequently engaged in the repetitive behaviour of slapping his face. He engaged with this activity with increasing frequency and force, sometimes also scratching and gorging at his face and causing infections. It was a safeguarding concern for staff, and a multidisciplinary meeting had been held to try to establish potential causes, solutions and strategies.

In this example, Simon, a non-verbal service user with severe intellectual disabilities and reduced vision, is sitting in his wheelchair wearing a painting apron. A plastic tray has been attached to his wheelchair and a canvas has been placed on it. Elvis, a support worker, is sitting on a chair to Simon's left and has his body oriented towards Simon, by sitting at a 90° angle on his chair. They are in the art room which adjoins another room, which is usually used by service users with mild-moderate disabilities. Loud music plays in the background and several service users can be heard interacting next door. Elvis has placed a plastic painting spatula in Simon's hand and is moving it across the canvass. Simon either has his eyes closed or nearly closed and is facing away from Elvis. With the exception of his hand which is being manipulated by Elvis, he remains still with his eyes seemingly closed throughout Extract 9 and for the majority of the 15 minute art session. There are no obvious interactional behaviours by Simon within the section analysed below. Please see Figure 24, Picture 1 for Simon's position throughout this example.
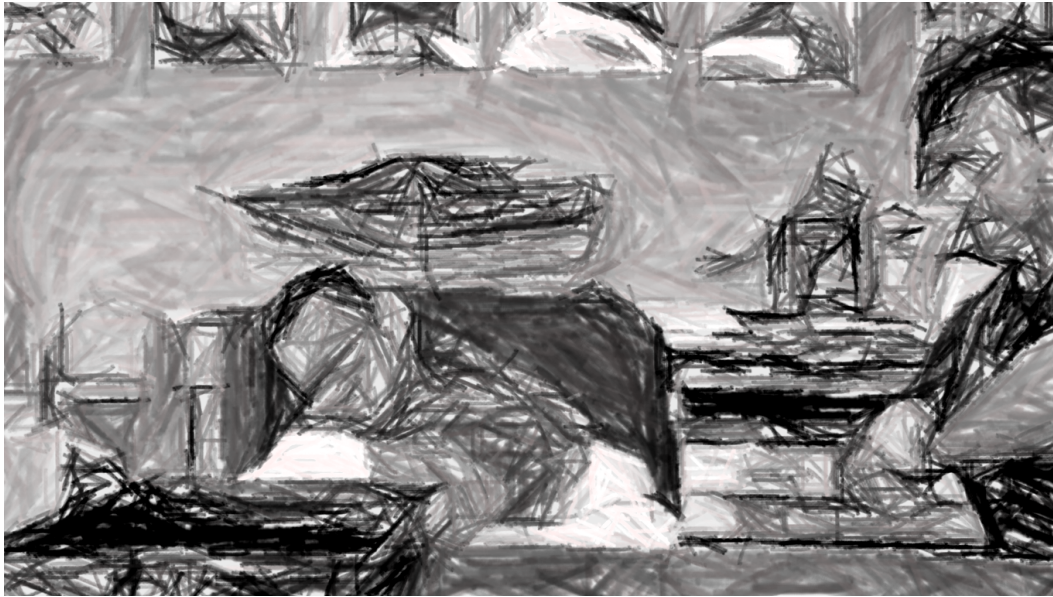
Figure 24 – Picture 1, Simon's position in art.

1	Simon:	((eyes closed, head and body positioned so they are pointing away
2		from Elvis and the canvas throughout the extract))
3	Elvis:	((places a painting spatula into Simon's hand and moves the end of
4		the spatula to make marks on the canvas))
5		[((withdraws his hand))]
6		[try doing that]
7	Simon	((leaves his hand relaxed and the spatula falls out of it))
8	Elvis	((picks up the spatula and replaces it in Simon's hand and guides the
9		spatula across the canvas by holding the end of it and by providing
10		over hand support for 9s))
11		((looks away from the canvas towards Simon's face))
12		[SIMON!
13		[((leans in towards Simon continues to look at his face for 1.5s then
14		returns to looking towards the canvas and Simon's hand))
15		(3s)
16		let's [turn that around
17		[((turns the painting spatula around in Simon's hand then continues
18		to move the spatula across the canvas for 6s))
19		°( ) just put it like this°

20		°Squeeze <u>there</u> °(.) Squeeze (.) push that up (.)
21		((maintaining his gaze towards the tray/Simon's hand he leans
22		towards them further))
23	Simon	((relaxes his hand slightly so the spatula falls through slightly and is
24		now in a different position in his hand))
25	Elvis	<u>Okay</u> (.) that's alright (.) cool
26		((moves Simon's hand across to the other side of the canvas))

Figure 25 – Extract 9, Simon and Elvis in art.

In this example, Simon's behaviours really are minimal. He does not vocalise, change his position from facing away from Elvis, open his eyes, or seem to move his hand independently - all of which he is physically able to do. Elvis orients to Simon's lack of interactive behaviours several times throughout the video. This can be seen by his use of the directive "try doing that" in line 6, his non-verbal behaviours of changing his position, proximity and eye gaze to attend to Simon's face in lines 11, 13 and 14, and using Simon's name as an attention seeking device in line 12. When these attempts fail, he reformulates the activity as something they must co-achieve in Line 16 where he utters "let's turn that around", (at least partially) accepting the role he plays within the activity.   Elvis then provides verbal and physical guidance on how to engage in the activity in lines 17-19 before giving more specific directives than he did in line 6, in line 20 outlining what he is encouraging Simon to do, namely "°Squeeze <u>there</u> °" and "push that up".   Despite his attempts, Elvis's behaviours do not elicit any response from Simon.

In a multi-disciplinary meeting relating to Simon's best interests due to his reccurring slapping behaviours, Simon's father and a team of professionals including senior management of the day care centre, his key worker, a speech and language therapist, two staff who supported Simon within his family home and a duty social worker, it was acknowledged that Simon would deliberately withdraw from activities "pretending to sleep".

It is noteworthy that this may require Simon to have a theory of mind, or an understanding of cause and effect and planning skills, which are not usually assumed in participants with severe intellectual disabilities. However, such skills were assumed by all professionals involved. All considered this as an increased risk for Simon as when he slept

family and staff monitored him considerably less which allowed Simon, on appearing to wake unobserved, the chance to engage in self-harming behaviours which were becoming a growing health concern.

The strategy of pretending to be asleep to resist activities has been observed and noted elsewhere. For example, Porter et al. (2001) discuss a person with profound intellectual disabilities being perceived to use the same strategy. Leudar and Fraser (1985) also discuss minimal engagement as a resistance strategy. Later in this section examples of participants potentially using this strategy whilst seemingly resisting different activities are provided.

Further evidence for Simon potentially using this strategy comes from Figure 26 - Extract 10, which details what happens immediately after Extract 9. This episode also occurred in the art session where Simon has demonstrated a lack of interactive behaviours throughout. It appears on the video as if Elvis slightly withdraws his hand-to-hand support from Simon. This is in line with his verbal behaviour which suggests that he is keen for Simon to engage with the activity with more independence. However, rather than taking up the activity, or continuing to be inactive - Simon lets go of the painting spatula and moves his hand to his face and begins to rub his face.

1	Elvis:	((tries to move Simon's arm by moving his hand to Simon's forearm and
2		pushing his arm, leaving the spatula resting in Simon's hand))
3		((Spatula comes out of Simon's hand in the air and lands on the canvas))
4	Simon	((lifts his hand upwards towards his shoulder/face with Elvis's hand still
5		gripping Simon's forearm))
6	Elvis	((moves Simon's hand down again with the hand which is on Simon's
7		forearm))
8		Hang on Simon (.) [I might just [adjust the apron
9		[((lets go of Simon's forearm and rips the plastic apron
10		from around Simon's neck))=
11	Simon	[((moves his hand up again))
12	Elvis	=((pulls the apron down and starts to put it on Simon's legs, looking down
13		as he does so))=

| 14 | Simon | =((lifts hand to face and rubs his eye with his paint-covered hand for 2.5s)) |
| 15 | Elvis | ((looks towards Simon and moves his hand down again – smiling)) hur huh |

Figure 26 – Extract 10, Simon and Elvis in Art 2.

In this example, it is unclear whether the spatula comes out of Simon's hand in line 3 simply because Simon is not gripping it appropriately for the movement of Elvis moving his arm in line 2, or if Simon deliberately releases it.   Either way, he demonstrates his ability to follow his own agenda of rubbing his face which he achieves in line 14. It is also possible that this is why Simon lifts his hand in line 4. It appears, however, that Elvis understands this behaviour to mean that Simon is uncomfortable with the plastic apron. He comments about adjusting it in line 8 and removes it from around his neck in line 9-10. It is, however, the movement of this apron which diverts Elvis's gaze away from Simon's hand and face, and down towards his legs where he places the apron (line 12).   This provides Simon with the opportunity to rub his face and for it to temporarily go unnoticed (line 14). This is demonstrated by Elvis's responses in line 15, where he moves Simon's hand, smiles and laughs.

After Extract 10, Simon returns to the position he is in in Figure 24 – Picture 1. For the rest of the session his behaviours return to minimal. Towards the end of the session Elvis comments that he believes Simon has actually fallen asleep, which is why he ends the session. Until then he continues to move Simon's hand to paint on the canvas, using different painting utensils and Simon's hand itself. Whether Simon is deliberately using the strategy of "pretending to sleep" or not, Extracts 9 and 10 demonstrate that although he may have been subdued with respect to engaging in the painting activity, in that instance, Simon was still able to rub his face (an activity which he spends much of his time doing. He is able to fulfil his own action agenda, but does not overtly challenge Elvis (for example by pulling his hand away from the hand-to-hand support) which he does very regularly in other interactions. An example of Simon attempting to withdraw his hand/arm from an object integral to the upcoming activity appears in Figure 29 - Extract 13.

To measure the success of any activity or interaction is difficult and subjective. Here, although I suggest that Simon minimally resists the activity, he is not actively

pursuing the potentially dangerous activity of rubbing, slapping or gouging himself that poses him a safeguarding risk while Elvis has his hand. He displays no signs of distress while Elvis is providing hand-to-hand support. Whilst it is clear that institutional and care agendas are being followed, and that social engagement and interaction is limited (despite the attempts Elvis makes), the activity provides some time where Simon at least appears relaxed and not an immediate risk to himself.

By way of further example, service users demonstrated minimal engagement during massage sessions. I filmed two sessions of Patrick receiving massages from the masseuse who visited the centre once a week. During these sessions, Patrick, who like Simon is very able to resist an activity, does not actively do so. The difference between a massage session and a painting session is that within a typically developed population one demands active involvement whereas the other does not. Whilst I suggest that Simon resists the active involvement that would be necessary for a successful painting session, it may be that the use of touch from the hand to hand support, the sensory stimulation which is provided from the art equipment and paint, or even the undivided attention and talk directed at him from a care worker, is intrinsically relaxing, soothing or enjoyable. After all, Simon is not resisting Elvis's touch in this extract.   A further example of Simon demonstrating no or minimal engagement with an activity is described after Extract 12.

10.3.1.2 Thomas and the advocacy group. I also made notes about another service user, Thomas, seemingly using this strategy, during his decline in functioning (see chapter 5 - Participants). When I first met Thomas he had some verbal abilities. However he had a significant delay ,often referring to topics that were discussed several minutes ago. Thomas could smile and frown and often engaged in prolonged periods of eye-contact. As his verbal ability was declining, it varied on a day to day basis. His receptive language was considered the best out of all the participants but was becoming more difficult to assess. Thomas spent a lot of time in bed during the time this was filmed because of a bout of ill-health involving several infections. On this occasion he was lying on his bed at Daisy Way. I had been in his bedroom that morning, chatting and listening to music for approximately an hour and he was relatively alert. Then, an advocacy group of seven members, comprising of one external member of care staff, one internal member of care staff, and five people with mild-moderate intellectual disabilities from

another local authority service, entered his room to see if he wanted to participate in an advocacy questionnaire. At this point, I left to provide additional space. I went next door and spent time with another service user. The advocacy group then came into that (considerably bigger) room to complete the questionnaire with that service user, saying that Thomas was not completing the questionnaire as he was too tired. After the other service user had completed the short questionnaire, I walked past Thomas's room. The door was open, so I knocked lightly and entered. Thomas lay there with his eyes closed. He then opened his eyes, saw me and very quickly tightly shut his eyes again. I said "Thomas!?" and he opened his eyes and looked at me with a big smile. I said that I wouldn't tell, and he continued to look and smile broadly at me. Without capturing this on video, it is not possible to give a detailed transcription of the event but I felt confident that Thomas was deliberately trying to "look tired" to avoid having to complete the questions the advocacy group had wanted to ask.

10.3.1.3 Jake having a foot spa. This extract involves Jake, a non-verbal man with severe intellectual disabilities, who used a wheelchair and was considered to communicate using physical movements, facial expressions and vocalisations. He is having a foot spa. A foot spa is a device which holds water. When feet are placed in the water, the foot spa then can be put on different settings to create bubbles, jets of water or move massaging rollers within the device, or a combination of these functions. In this example, the foot spa has been placed on a box so that Jake's feet can reach it. He has had his feet in the water for approximately 20 minutes and demonstrated several potential signs of resistance during that time. These are discussed in the below. During this session, Eric is supporting Jake. Prior to this extract Jake had placed his hand in his mouth 15 times in the video, the last time being approximately 10 seconds before the start of this transcript.

1	Jake	((leans slightly to the left of his wheelchair with his eyes open))
2	Eric	((walks over to Jake holding a bottle of squash in one hand and box of
3		milkshake powder in the other))
4	Jake	((moves his head and looks up towards Eric's face for 0.5 and then moves his
5		head so it is facing down towards the floor and closes his eyes))=

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6	Eric	JAKE
7	Jake	=((continues to face downwards clicking his tongue))=
8	Eric	<u>Jak</u>::e
9	Jake	=((continues to face downwards clicking his tongue for 2s))
10	Eric	[¹hell:::o (.) I'm h[²ere]
11		[¹((moves the bottle and boxes around in front of Jake's face))]
12	Jake	[²((moves his head upwards from facing the floor[opens his
13		eyes and closes them again, keeping his head in an upright position))
14	Eric	[HELL<u>:::O</u>
15		(.)HELL<u>:::O</u> (1.8) pretend to be sleeping I don't mind

Figure 27 – Extract 11, Jake having a footspa and Eric offering a drink.

After this Eric spends a further 1 minute 20 seconds trying to elicit a choice of drink from Jake. Although at times Jake opens his eyes, he does not offer Eric any other response. Eric then abandons trying, explaining that Jake is not interested and that he will try again later.

In this example it appears as if Jake's behaviours in lines 4-5, where he lowers his head and shuts his eyes, are in direct response to Eric's arrival in lines 2-3. Eric tries to engage Jake by use of his name (lines 6 and 8) and use of the word hello (line 10, 14 and 15), both calls for attention. Although Jake does open his eyes in line 12-13, he closes them again immediately after. Eric even verbalises his understanding of Jake's behaviours to demonstrate that Jake is deliberately choosing to exhibit minimal behaviours to appear asleep in line 15 where he says "pretend to be sleeping I don't mind".

10.3.1.4 Simon in gait trainer (1). In this example Simon, the participant who regularly slapped/rubbed his face, has been placed and secured into his gait trainer by care staff member, Saheb. Simon is non-verbal but is considered to communicate through moving his face and body, facial expressions and vocalising. Simon's gait trainer consists of a wheeled frame with a harness attached. Simon is then secured to the gait trainer using Velcro strips arounds his arms. This device is used both to enable Simon to walk and improve upon his walking skills. Simon's resistance getting into the gait trainer is discussed in the subsection below.

Whilst Simon appears to resist actively somewhat as Saheb secures the gait trainer, once this has occurred, Simon's resistance is not overt. Instead his resistance/disengagement is demonstrated through minimal engagement. Throughout the whole session Simon barely moves from his slouched position, with the vast majority of the session spent with his head facing the floor and his feet dragging along it. His eyes also appear to be closed.   For the entirety of the session Saheb pushes the gait trainer around, something that Simon, at least usually, has the physical ability to do himself.

Saheb is, however, trying to encourage Simon's behaviours by using verbal prompts and acknowledges Simon's minimal engagement. This is demonstrated in the extract below.

1	Saheb	((looks to camera)) he doesn't want to walk [today]
2		[((shifts gaze back towards
3		Simon))]
4		(1.5)
5		are you <tired>
6	Simon	((rubs/kicks the back of his right leg with his left foot for 3.5))=
7	Saheb	[let's walk about ((moves around the back of the gait trainer and starts
8		to push Simon and the gait trainer around))]
9	Simon	=[((continues to rub/kick the back of his right leg with his left foot until
10		the gait trainer is moved and then he stops))]
11	Saheb	((pushes in silence for 7s, looks to the researcher and points to his left))
12		let's go that side (.) if you go there
13	CN	[((moves to directed place))]
14	Saheb	[yea yea]
15		((pushes gait trainer in silence for 8.5s)) [can I walk him [↑a↓round]
16		[((continues to push gait
17		trainer))=
18		[((makes a circle
19		with his left index finger]))

20		=((continues to push gait trainer))=
21	CN	°yea°
22	Saheb	=((continues to push the gait trainer))=
23		make him awake (4s)) <u>come on Simon (1) wakey wakey (3.5) wakey</u>
24		<u>wakey (.)</u>
25		=((turns the gait trainer around at the end of a corridor, looks to the
26		floor/Simon's feet and stops))=
27		[put your foot down properly]
28		[((bends down and moves Simon's feet so that they are on the floor,
29		rather than crossed and dragging))]
30	Simon	((moves his feet slightly so they are crossed again and not flat on the
31		floor))
32	Saheb	((starts pushing again))
33		Come on come on (.) >wakey wakey wakey wakey wakey wakey< SIMON
34		

Figure 28 – Extract 12. Simon in the gait trainer with Saheb

At the beginning of this extract, Saheb expresses that he believes Simon "does not want to walk today" , choosing to use the word "want", suggesting that Simon had a choice as to whether he was to engage in the activity of walking. Although in line 5 Saheb offers a candidate reason as to why Simon may not want to walk today (him being tired) Saheb begins this extract as at least framing Simon's minimal engagement as a choice, rather than Simon being incapable of completing the task.

When the gait trainer is being pushed, Simon's behaviours are limited. Simon's eyes remain closed, his position slouched and his face in a downwards position, towards the floor. Saheb tries to encourage Simon's engagement by verbal prompts including use of Simon's name and repetition of the terms "come on" and "wakey wakey" (lines 23, 24 and 33). In English, "come on" is an imperative phrasal verb used "when encouraging someone to do something or to hurry up or when one feels that someone is wrong or foolish." "Wakey wakey" is defined as "an informal exclamation used to rouse or wake someone" (OED, 2018). Both orient to Simon's inactive state. The only response that Simon offers within the extract is in response to Saheb moving Simon's feet (in lines 30-

31) whilst providing the verbal prompt "put your foot down properly". Simon resists this change, slightly moving his feet so they are not flat on the floor, but behind him, crossed, dragging along it – as they were previously.

This example, like extract 9 (example of Simon in art), captures a theme that occurred several times within my ethnographic notes, namely staff members seemingly carrying out an activity "on behalf" of a service user. This regularly happened despite noticeable disengagement or resistance from service users. I observed this across a variety of activities (see the Discussion section for further details).

10.3.1.5 Minimal engagement/disengagement overview. Behaviours used to demonstrate minimal engagement/disengagement included service users closing their eyes, positioning away from activity equipment and staff, and being in a slouched position. A lack of vocalisation was also a feature of the examples. Not exhibiting behaviours that are integral to activities (such as holding painting equipment in art or walking whilst in a gait trainer) also demonstrate disengagement.

In this section real-life examples of a withdrawal/resistance strategy that have been reported in participants' notes, as well as in the related literature, are provided. These examples provide support to the idea that people with severe intellectual disabilities may choose to be non-responsive to the extent that they may look asleep. Staff referred to this explicitly several times in my dataset.   Examples in sections 10.3.1.2 and 10.3.1.3 demonstrate the participants being considerably more responsive immediately before or after resisting particular activities suggesting that the non-responsiveness is unlikely to be due to a genuine physical state, such as tiredness and/or drowsiness caused by medication. That said, in some cases it may be that medication and/or tiredness is the reason why   participants appear to be sleeping. It is always difficult to determine which behaviours are intentional. However, even if the minimal responses are non-intentional, they still clearly signal that the person is not able, willing or ready to engage in the activity in question at that time. This idea is expanded upon in the next chapter Mealtime Interactions (chapter 11).

Whilst minimal engagement in an activity, particularly "pretending to sleep" may be a strategy used by people with severe intellectual disabilities, some certainly use it more than others. For example, I captured several examples of Simon seemingly using

this strategy but I could not find a single example of Jenny using it, either in my ethnographic notes or on video.

10.3.2 Resistance to an activity.

10.3.2.1 Simon in a gait trainer (2). At the start of this transcript Saheb has finished securing Simon into the gait trainer. Simon has already been supported into the harness section and has had the Velcro secured around his arms.

1   Simon   ((rubs/lightly kicks the back of his right leg with his left foot))=

2   Saheb   [>com[e'on come'on come'on<]

3   [((gently taps Simon's back in rhythm with his speech))]

4   Simon   [((turns head towards floor and remains looking down))]

5   Saheb   [((undoes the Velcro strap around Simon's wrist and pulls his sleeve

6   down and goes to resecure the strap on Simon's wrist so that it is

7   over his clothing))=

8   Simon   =((while continuing to rub/kick the back of his right leg with his left

9   foot he reaches and stretches out his left arm which is being re-

10   velcroed to the frame, [his fingers are visibly tensed and splayed))]

11   Saheb   [((places hand around Simon's wrist as he is moving it backwards

12   and down – back towards the frame of the gait trainer frame] and

13   tries to hold it there))

14   [NO (.) come'on (.) Simon

15   (.)>Simon (.) Simon Simon<

16   ((holds Simon's forearm down on the frame))=

17   Simon   [((despite Saheb holding his arm, begins to move his hand towards

18   his face))

19   Saheb   [((=continues to hold Simon's forearm down towards the frame

20   Simon   ((moves his arm outstretched and jerks his elbow backwards))

21   Saheb   ↓a::h come'on man[((holds Simon's wrist and pushes it down onto

22   the frame and resecures the strap))]

23   Simon   [((kicks harder and more frequently than before, slightly rocking,

24   outstretching his fingers))]

25   Saheb   [((lifts Simon's arm by the wrist and moves it backwards, back onto

26   the gait trainer arm rest and finishes re-secures the Velcro strap))

Figure 29 – Extract 13 Simon in gait trainer with Saheb 2.

In this extract, Saheb treats Simon's non-verbal behaviours in line 1 as a sign of resistance to being secured in the gait trainer This is demonstrated by his talk in line 2, where he repeatedly tells Simon to "come on" which is accompanied by physical prompts in line 3. The use of "come on" in line 2 not only implies that Simon should somehow

change his behavior (of rubbing/kicking his leg) but that he should do so in order to complete a different line of action (being secured into the gait trainer) to the one he was already engaged with. However, Simon does not. Then Saheb goes to adjust the Velcro strap on the arm-rest of the gait-trainer. At this point, Simon's behaviours are not so disruptive that they significantly interfere with Saheb continuing the task that he had been doing before the start of the extract, namely securing Simon into his gait trainer, which he continues to do in line 6. It is in lines 8, 17, 20 and 23 that Simon attempts to launch an action which is in direct conflict with Saheb's action agenda. In line 8-10, Simon first begins to demonstrate the behaviours which necessarily happen immediately before he rubs/slaps his face, namely outstretching his arm, tensing his hand and moving his hand towards his face. Saheb's next turn, in lines 11-15, orients to Simon's pre-slapping behaviours as Saheb directly opposes them verbally, initially directly by saying "NO", then by encouraging a change of Simon's trajectory of actions by repeating his earlier utterance of "come on" before saying Simon's name four times. He also resists Simon's actions by holding down Simon's arm in lines 16, 19 and 21. As is demonstrated in the lines that follow, it is Saheb's institutional agenda of securing Simon into the gait trainer which is fulfilled (in lines 25-26) despite Simon's continual physical resistance.

This extract differs from Extract 10. There Simon tries to rub/slap his face which he pursues only when his hand is free to do so. Here, Simon is actively resisting being secured into the gait trainer in favour of completing his own agenda. It should be noted that using the gait trainer more frequently as an activity which restrains Simon from his self-harming behaviours was a strategy which was raised at the multi-disciplinary meeting referred to previously. It was agreed as a short-term solution by various health care professionals. This was seen as a potential solution but one carer noted that when Simon was particularly motivated he could lean his face into the Velcro on the trainer and rub his face against it.

10.3.2.2 Jake leaves music. In this example Jake, a service user, is being supported by Eric in a music session. Jake is non-verbal and usually uses a wheelchair, although in this example he is not in it.   The session is taking place in a large room in the day centre. There are approximately 20 people, with both staff and service users present. The severity of intellectual disability of those present varies from mild-moderate to severe. Many have good verbal abilities. Percussion instruments have been given out to staff and

service users who would like to use them. These weekly music groups, if joyous, are regularly particularly noisy and not always tuneful. Jake has been taken downstairs to the music group on his scooter. Jake's scooter has been especially made for him. It is a square block of foam with four small wheels attached to the bottom. One of the top edges has Jake's shape cut out, which he sits in, making it like a small seat. When sitting in his scooter Jake's feet touch the floor and he uses them to propel the scooter unaided. Jake's scooter increases his ability to move around independently and often when he uses it he is able to explore the environment as he wishes. As this extract is 14 minutes long, I have summarized the details and trajectory of the interaction in prose.

At the beginning of the video, Jake is upstairs in the general room in the day centre where he was moving around freely. He appeared to be happy. He was vocalizing, (which sound like ahh and ohhh) and smiling widely. However, later when Jake is downstairs he appears to demonstrate his resistance to participating in the music session in different ways.

First, when Jake is moving around on his scooter travelling down the corridor from the lift, still smiling and vocalising, he tries to avoid going into the room where the music session is going on by continuing to move down the corridor instead of going into the music room. However, Eric places his hands on Jake's shoulders and asks "Jake are you here for music group? This way for music group yea?" He then pushes the scooter into the room where the music session is taking place.

Immediately after this Jake begins to "scoot" himself out of the room. When Jake leaves the music room he is smiling widely and seemingly happily vocalising. Jake also stops and looks back towards Eric several times – perhaps suggesting he is enjoying that Eric is following him, or checking to see if Eric will stop his line of action, maybe allowing him control of the interaction. He also stops and leans to look around doors and corners as he comes across them throughout. This is something Jake tends to do when he is in his scooter and is listed in his communication passport as something he enjoys doing. Jake heads along a corridor to the physio room which happens to be empty. Jake enters the room followed by Eric. By this time Jake's facial expressions are more neutral but he is still vocalizing in a similar way and appears at very least to be content. Whilst in the room, Eric takes a seat. After 45 seconds of being in this room, Jake begins to leave and scoots himself towards the door and back down the corridor.

When Jake reaches the hallway near the music room he stops and leans around the door slightly. Eric once again pushes Jake into the room where the music session is taking place , this time doing so by placing his hands directly onto the scooter and pushing it. He then places his leg behind the scooter apparently in an attempt to stop Jake moving around in it. Instead, Jake simply moves forward and then right , freeing himself from Eric's constraint. Eric goes to follow Jake's movement and goes to put his leg behind the scooter again but quickly retracts, perhaps influenced by the presence of the camera and researcher. Jake then turns himself around 180° and once again heads for the door.

Having left the room this time, Jake heads for the lift. Once he reaches it, he vocalizes ("ERR↓rr↓rr") and reaches out his arm towards the lift and moves it from left to right three times (see Figure 30 – Picture 2).
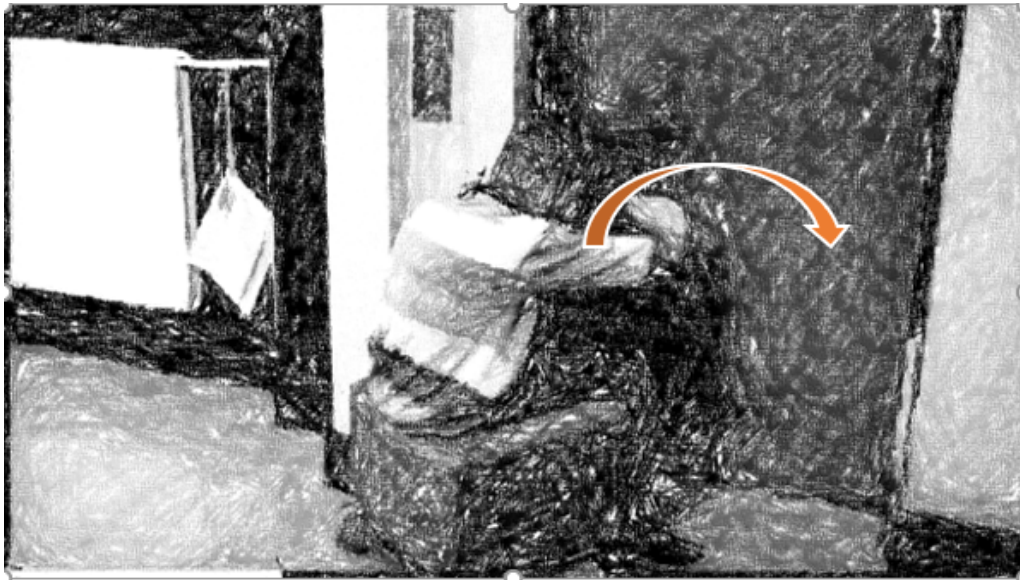
Figure 30 – Picture 2, Jake reaches for the lift with arrow added to show his hand movement.

 He also clicks his tongue. Eric comments "he wants to go upstairs", but does not enable him to do so. Jake makes a louder, deeper vocalization than before (UR::HM!) and stamps his foot three times. He then continues to look at the lift, vocalising softly and occasionally banging his foot. Eric does not respond to these behaviours. After 1 minute and 20 seconds, Jake abandons the lift and begins to move about again. When Jake reaches the hallway where he can either go down the corridor to the empty physio room or into the music session, he begins to head for the corridor. Eric utters "Jake!". Jake

stops and turns his head around and then Eric says "Come on Jake, come with me" and once again pushes the scooter into the room with the music session.

Soon after they have entered the room Jake places his feet flat upon the floor, physically resisting Eric's push of the scooter further into the room where the music session is going on. Eric waits approximately 4 seconds and begins to push again. Although Jake still has one foot flat against the floor, Eric is able to push the scooter again. He positions Jake near the other service users and staff and brings a chair to sit behind him. This time he does not constrain the movement of the scooter with his leg Instead he keeps hold of the scooter with his hands making it impossible for Jake to move away.

Jake tries to move the scooter as before, but can only move it slightly side to side. Now he can move it only a matter of inches compared to being able to move freely and independently. He looks down and lifts his right arm into the air. He then tries to move again and Eric moves the scooter closer to him to restrict Jake's movement further. Jake lifts his right arm into the air again, three times. He then reaches over to a nearby chair and pushes it, potentially in an attempt to "propel off it", but this cannot be said for certain. For the next minute and 15 seconds, Jake continues to try to move and Eric continues to hold the scooter. Jake raises his arm again twice. Then he tries to push the chair again twice. Jake is noticeably going red in the face. Whether this is because of the physical exertion of trying to move or associated anger after not being able to, or a combination of both, this is a physical signal he is becoming increasingly uncomfortable in the situation. Jake reaches for the chair again and Eric moves it out of reach. Jake then thrashes his body, including his arms which hit his head slightly before self-harming by digging his finger nails into his hands and drawing blood. At this point the camera was turned off for ethical reasons.

When I asked Eric after the recording about why Jake left, he responded that "he wanted to go upstairs" and when I asked why he kept bringing him back, he responded that he was "down to do music" and suggested that "he shouldn't be on his scooter, that is a different activity".

This example differs from those discussed above. In the examples involving Simon although institutional agendas are being followed, they are concerned with both minimising risk and maximising engagement (though that is not necessarily suggesting

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they were fully successful in doing so). However, there was no logistical or safeguarding reason why Jake could not be on his scooter moving around the areas of the day centre, most of which were empty and which he could have been free to explore. At the start of the video, when Jake was permitted to do this, he was vocalising with varied high pitch and smiling widely. Whilst I acknowledge that institutional agendas are often followed with due consideration for a person's rights (for example stopping self-harming behaviour endorses that person's right to be safe) this instance appears to be an example of an institutional agenda being blindly followed without consideration as to why it is necessary to do so.

In this example, Jake demonstrates his resistance to joining the music session in a number of ways. He leaves the room three times, something he would not have been able to do had he not been in his scooter , demonstrating how physical mobility can aid people with severe intellectual disabilities to express choices. He also goes to the lift and demonstrates behaviours understood by both care staff and myself to signal that he would like to enter the lift which would take him further away still from the music session. The contrast to Jake's wide smiles and "excited sounding" high pitched vocalisations which occur when he is able to move around freely and the lack of these behaviours is stark. Additionally, Jake physically resists the movement of his scooter by placing his feet flat on the floor. Jake lifting his arm in the air also appears to demonstrate his resistance and also occurs in extracts in Chapter 11, Mealtimes . Finally, continually trying to move, even when being constrained and finally thrashing and self-harming are also resisting behaviours.

On examination of Eric's behaviour, it appears that a different approach might have been adopted. He does not appear to treat Jake's apparent choices as legitimate. Even when he verbalises his understanding of Jake's behaviours ("he wants to go in the lift") he does not provide the required response to fulfil Jake's wishes (namely pushing the button for the lift). He continues to bring Jake back to the same room, even though Jake keeps leaving it and he eventually forces Jake to stay in that room, which arguably contributes to the reason Jake gets so distressed and eventually self-harms.

10.3.2.3 Jenny in art. This extract involves Jenny, a service user with severe intellectual disabilities, and Monty, a member of care staff. Jenny is not verbal but regularly vocalises. She is mainly considered to use facial expressions, use of gaze and

vocalisations to communicate. She also uses her posture (as described in chapter 9, Relationships). They are in a side room at the centre which is adjoined to a busier room where there are many service users and members of care staff.   At the start of this session another service user is present, sitting silently in a chair, but he soon leaves. Neither Monty nor Jenny explicitly attend either to his presence or his departure. Jenny is in her wheelchair and has a painting apron on and a small table has been set up with painting equipment. Monty is to her right hand side at a 90° angle.

1	Monty	what do you think of these colours?
2		((pushes Jenny's chair further towards the table with the painting
3		equipment on it))
4		Hmm ((moves the paint on the table to be directly in front of Jenny))
5		Tell me, first shall we start with the [purple] or the [blue]
6		[((picks up purple paint pot and
7		places it in his hand))]
8		[((picks up blue paint
9		so he is holding the purple paint pot in one hand and the blue paint pot
10		in the other))]
11		cause I'm not sure which one's the best (.) hmm (.) what you thinking
12	Jenny	((looks up towards Monty - away from the paint and the camera))
13	Monty	[↑I like them both↓] don't you, ((smiles)) is that what you're saying [to
14		me]
15		[((wobbles his head))]
16	Jenny	[((looks down towards the paint))]
17		((places her hand on the purple tub of paint, also touching Monty's
18		hand))
19	Monty	Purple ((moves his hand and the paint pot back to the table))
20		RIGHT (.) OKAY (.) [cause Lucy likes purple as well doesn't she]
21	Jenny	[((looks towards Monty and back straight ahead
22		again))]
23	Monty	shall we have three colours?

24	Jenny	((looks towards Monty, then turns her [body to Monty smiling widely))]
25		[>what you think<]
26		((turns back, still smiling))
27	Monty	((lifts three bottles of paint)) here (.) these ones
28	Jenny	((leans back slightly standing in her chair, eye gaze towards Monty's face
29		and then fully sits again and touches the bottom of the white paint))
30	Monty	white (.) [white (.) good (.) right]
31	Jenny	[((grips bottom of the white paint bottle Monty is holding and
32		pulls it towards her with closed nozzle end nearest to her, looking down
33		at it))]
34	Monty	[Well you can't] put it on your clothes
35		[((takes the paint out of Jenny's hand and puts it on the table))]
36		((turns around facing the camera and back straight ahead again))
37		((holds the red and green paint bottles in front of Jenny)) shall we do one
38		more colour (0.2) green or red? ((swaps the red and green paint position
39		with one another)) I'll put it that way ( ) >green or red (.)
40		green or red<
41	Jenny	((reaches out and touches Monty just above the elbow, pushing it slightly
42		away and leaves her hand there looks around slightly, back at the camera
43		smiling slightly))
44	Monty	None of them (.) so you just want purple and white
45	Jenny	((pushes Monty again and moves her hand back to her lap))
46	Monty	A WISE CHOICE
47	Jenny	((Puts her arm in the air and looks towards it))
48	Monty	((places the paints back on the table))
49	Jenny	((pulls at the front of her apron))
50	Monty	Woah woe woe
51	Jenny	((pulls her hand and arm inside the sleeve of the apron and starts
52		flapping her right arm so the loose end of the apron is moving side to
53		side))=
54	Monty	Jenny

55		=((starts to put his hand up the sleeve of the apron))
56		Gimmie that hand! (.) gimmie that hand back
57	Jenny	((starts pulling the body of the apron off herself))=
58	Monty	((looks at camera)) She doesn't wanna paint. You get the feeling she
59		doesn't want to paint ((smiles))
60	Jenny	=((continues to pull the apron off herself))
61	Monty	You don't wanna paint (.) okay

Figure 31 – Extract 14, Jenny and Monty in Art

This transcript is longer than most in an attempt to capture the overall trajectory of the interaction. Near the beginning of the interaction Monty offers Jenny a choice of paints, purple or blue. He does this verbally (line 5) and by physically presenting the paint pots (lines 6-10). This does not initially get a clear response from Jenny, but she soon looks towards (line 16) and touches one of the paint pots (lines 17-18). Monty then suggests using two more colours and also physically presents a choice of three (lines 23 and 27) to which Jenny seemingly provides a delayed response by touching the white paint bottle and pulling it towards her (lines 28-29 and 31-33).   Whilst Jenny's responses have not been immediate, until this point in the interaction it appears that Jenny's actions are aligned with Monty's, both completing actions necessary to undertake the upcoming art session.

However, in lines 37-40, Monty provides the final choice of paint, again presenting the physical objects alongside. In Jenny's next turn (lines 41-43), she gently pushes Monty's arm, leaves her hand there and smiles. In line 44, Monty demonstrates his understanding of this as Jenny refusing the offer of an additional painting colour. Then, from line 47, Jenny begins the process which allows her to remove herself from the apron. This continues and is more obvious in line 49. Monty then says "Woah", which in English is a term to encourage slowing down and was originally used "to express surprise, interest, or alarm, or to command attention" or "urge a person to stop or wait" (OED, 2018). Jenny continues removing the apron (line 51) and Monty begins to try to encourage her not to, both physically, by reaching for her arm in the sleeve, and verbally (55-56). But after she continues removing the apron in line 57, he directs his talk to the researcher and verbalises his understanding of Jenny's motivation for removing the

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apron, because she does not want to paint. Soon after the end of this transcript the activity is abandoned.

It is unclear whether Jenny changed her mind about painting during this interaction or whether some of her behaviours were misunderstood. For example, it is possible when she was reaching for the paints that she was just trying to touch Monty's hands and never had any interest in painting. Equally, she may have become warm in the apron, or not liked the fact the sleeves were slightly too long for her. She may have happily painted if solutions were provided. It may be that she was being playful with the apron, something she was understood by staff to do often with plastic aprons. Unfortunately, we will not be able to ascertain these reasons. What we can take from the extract is that Monty comes to understand Jenny's removal of the apron as resistance to the art session in general. He only comes to this conclusion after suggesting that some signs of resistance (gently pushing his arm in lines 41-43) were resistance *within* the activity (resistance to selecting an additional colour) rather than *to* the activity as a whole (resistance to the whole art session), which he only suggests after Jenny is involved in the process of removing the apron.

After the art is abandoned, Monty supports Jenny out of her wheelchair so she can move around freely on her kneepads. Whilst this gives Jenny more independence, he does not provide any further interaction for Jenny. She spends 10 minutes after the session sitting on the floor alone. Whilst it is possible that Jenny did not want to complete art, this does not necessarily mean she does not want to be social. Perhaps it would have been wise to offer another activity which promotes social interaction.

10.3.2.4 Overview of resistance to an activity. In the examples in this section, participants appear to demonstrate resistance by physically moving away from the activity, trying to remove themselves from equipment related to the activity, or removing related clothing. Other examples of resistance included trying to complete competing courses of action (such as slapping or rubbing their face when hands/arms are needed for other activities), including self-harming. Participants also pushed staff away and stamped their feet. Some participants appeared to have individualised ways to signal resistance. For example Jake held his arm in the air and Simon would kick his legs.

It is important to note whilst all of these behaviours were demonstrated within the context of service users resisting activities, some of them may have been specific

resistance to certain staff behaviours that occurred as a result of the service users resisting activities. Staff responses to potential resistance differed in the examples presented within this section. In the example of Jake leaving music (in subsection 10.3.2.2), despite Jake repeatedly demonstrating his unwillingness to participate in the music session, Eric did not treat this decision as legitimate. Jake's behaviours towards the end of the extract are likely to be resisting Eric's responses and not just the activity. By contrast, in Extract 14, Monty quickly treats Jenny's potential resistance as a clear sign that she wants to terminate the activity, even before fully exploring any additional potential explanations.

10.3.3 Resistance within an activity.

10.3.3.1 Jake leaves music and returns. Apart from the example in subsection 10.3.2.2, I have two other filmed examples of Jake during music sessions. Both sessions are held in the sensory room within the day centre, a smaller room than the dining hall where the session was held in the extract above. In these examples, Jake is in his wheelchair instead of his scooter. However, he still demonstrates some signs of resistance by movement during these sessions and in both examples was supported to leave the music room for short periods of time before returning. In the example below Jake is being supported by Baruk.

In this session the group is listening to a Christmas CD, singing along and playing percussion instruments. Baruk and Jake are sitting side by side. In the first three minutes of the video, Jake's behaviours are minimal and are similar to those presented in the "no/minimal behaviours section" above. Largely his eyes are closed, and his face is positioned towards the floor. He is slightly more alert in the 4th minute, and he is given a maraca twice but each time he does not keep hold of it and it falls to the floor. By the start of the 5th minute where this extract starts, Jake is more alert facing forwards with his eyes open. Just before the start of this extract the song had stopped and a staff member had requested the Christmas song "Silent Night". One member of staff is handing out lyrics.

1   Jake   ((leans forwards in his chair slightly, bending right slightly towards

2   the door then leans back and remains still))

3   Baruk   ((shakes the maraca for 3s then leans around to look at Jake's face))

4   Jake   ((moves his face around towards Baruk))

5   Baruk   ((sits back again then continues to shake maraca moving it close to

6   Jake's face then away again))

7   (1.5)

8   ((singing very out of tune while shaking the maraca)) S::ILENT NIGHT

9   Jake   ((starts to rock slightly pushing forward in his wheelchair))

10   Baruk   ((shakes maraca in the air towards the person giving out lyrics))

11   ((sings)) HO::LY NIGHT

12   A:::L:::L IS BRIGHT [((shakes maraca quickly)) [A:::L:::L IS BRIGHT]

13   Jake   [((moves his wheelchair forward by rocking more

14   significantly))]=

15   Baruk   [((leans towards Jake

16   shaking his maraca quickly))]

17   Jake   =((continues to lean and move forward and to the right, towards the

18   door of the room))

19   Baruk   Heh heh heh heh

20   Jake (0.5) you want to take a [walk around the corridor?]

21   [((puts his hand on the handle of Jake's

22   wheelchair))]

23   [↑Ja↓ke]

24   [((pulls the wheelchair back))

25   Jake   ((continues to rock))

26   Baruk   [Alright]

27   [((stands and walks out of the room with Jake))

Figure 32 – Extract 15, Jake and Baruk in music.

Within this session, despite being in his wheelchair Jake manages to move slightly towards the door by rocking back and forth (lines 9, 13-14, and 17-18). He only begins

this behaviour after Baruk starts singing in line 8. Baruk is a friendly, lively member of staff but I am sure he would accept that singing is not his strong point. He sings loudly and out of tune. During most of this music session there is a CD playing but this is not the case during this extract. Baruk laughs in line 19, potentially at his own singing (which includes incorrect lyrics in line 12) or at the fact that Jake appears to be moving away from him while he is singing and playing the maraca. Baruk responds to Jake's movement towards the door by offering to go for a walk in the corridor, which they then do. Soon after, they return to the session and stay for the remainder. This demonstrates how although people with severe intellectual disabilities may show signs of resistance during certain activities, the signs of resistance may alleviate, be temporary or relate to a specific element of the interaction. For example, in this example it is possible that Jake's resistance was specifically to Baruk's loud singing. After having a break these signs of resistance (particularly rocking in his wheelchair) alleviate.

   10.3.3.2 Simon in physio session. This filmed interaction which included several examples of Simon potentially resisting particular courses of action, or activities, was during a physio session. Simon is in the physio room at the day centre with two other participants with severe learning difficulties, Jake and Jenny. Care staff, Lacey, Luke and Monty, are all present. Each member of staff has been assigned a person to support during the physio session and Monty has been assigned Simon. Throughout the session, Simon has been alternating between rocking backwards and forwards on a large red physio ball and sitting on the mat. Whilst sitting on the mat he regularly slaps his own face, a behaviour Simon often exhibited. There were, however, some other activities during the physio session. In the example below Simon has been standing, supported by Monty. See Figure 33 – Picture 3 for exact positioning. He also spent some time sitting on a foam roller.

   In this example, Simon has recently abandoned bouncing on the red ball which he was completing with Monty, and has moved away from it on his knees. In doing so he has also come off the large foam physio floor, that has been laid out throughout most of the room, onto the carpet. Monty, blocks Simon's path by moving into it. Simon then shuffles around, approximately 60° at a time, three times – so he is now facing the other direction. Monty follows Simon with each turn, jokingly asking "where you going" three times. Then Monty puts his hands palm upwards in front of Simon as askes "wanna

stand up?" It appears that Monty has understood Simon's resistance to being on the red ball and is offering another physio activity, standing. Monty then repeats the question, as Simon moves his face away from Monty, then Monty takes Simon's hands and raises them slightly, saying "Come'on" twice. At first, Simon appears uncooperative. He does not raise his arms himself, look at Monty, or otherwise provide a clear response. Monty acknowledges this by asking "No?" However, Simon then rocks himself back, then forth and into a kneeling position.

Although Simon demonstrated resistance towards staying on the red ball, this was resolved by offering him another physio activity. Whilst his actions at first, may look like resistance, Simon then engages with the activity of standing, by preparing to do so by moving onto his knees. It appears that Simon may have needed the extra time and encouragement to prepare his movements (for example rocking back and forth before moving from sitting to kneeling).

Once Simon is in a kneeling position, Monty places his hands underneath his armpits. Within a few seconds, Simon rises from kneeling to the standing position shown in Figure 33 – Picture 3. This supports the idea that Simon kneeling was a pre-cursor to him standing.

Figure 33, Picture 3 – Simon standing supported by Monty.

Monty and Simon then stand together and begin walking towards a wall as part of the physio activity. They stand together for approximately 1 minute. Simon bends his

legs, rocks back and forth and bounces slightly. He spends some seconds vocalising, producing low, pant-like vocalisations. However, after a minute Simon moves his foot quicker and stamps it twice. He also bends his knees considerably lower than he had previously and rocks faster, gripping onto Monty's shirt as his pant-like vocalisations become faster and louder. Monty interprets this as Simon wanting to assume a position on the floor, which he changes his own position to support (see Figure 34 – Picture 4).

Figure 34 – Picture 4, Monty changes position to assist Simon

However Simon does not continue to bend to the floor. Monty then utters " right there, okay?" and Simon stands more upright again and Monty says "Oh! You don't want down!" Nineteen seconds later Simon wails and pulls down toward the floor. Monty once again changes his position, bending his knees and moving his hands as to support Simon to sit on the floor. This time Simon bends his knees fully and sits on the floor. Monty comments that Simon does not usually stand for that amount of time. Then, within 6 seconds, Simon begins to slap his face which Monty responds to by placing his hand on

Simon's hand. After 11 more seconds, Simon lies on the floor with his eyes closed. Whilst he looks asleep, he occasionally moves his arms and rubs his face on the mat. This continues for several minutes.

This could be because Simon was actively resisting continuing with physio activities such as standing and walking. Whilst Simon appeared happy to complete some standing and walking, as Monty commented, he does not usually want to do this for a prolonged period. It may also have also been that he did not want to complete this activity for a prolonged period of time because of the physical and cognitive demands that accompany it. He may have been tired after completing it and simply wanted a rest. His intentionality is questionable. Yet, his behaviours appear to demonstrate that at those moments, he is not ready (attending, willing and able) for whatever reason, to complete physio-related activities. This example differs from the examples discussed in the earlier section of no or minimal engagement, as Simon is disengaging intermittently, whilst at other times seeming fully engaged, something that did not occur in the examples presented earlier.

Other resisting behaviours Simon exhibited during the hour physio session included leaning away from a physio roller or red physio ball on which he was positioned and physically moving away from staff. At other times, he seemed quietly content engaged in rocking back and forth on the ball. Similarly, in the extract described above, he appears to want to remain standing at one point (when he resists Monty's support to the floor) but soon after wants to go back to the floor. His resistance to the physio activities appear to be both time and activity dependent.

10.3.3.4 Overview of resisting within activities. The examples in this chapter demonstrate how resistance to an activity is not necessarily permanent. Service users may be resisting certain aspects of the overall activity but may not be demonstrating that they do not want to participate at all in the session. For example, Jenny may resist playing a tambourine but be happier with a maraca or may resist being left without social engagement with an instrument but is happier when staff attend to her. This should not be taken to indicate that all demonstrations of resistance are temporary. How to distinguish between resistance within and to an activity is not simple. This is demonstrated in Extract 14 where it is ambiguous whether Jenny resists painting,

complains of her lack of social contact or is simply being playful by removing her apron as seen in chapter 9.

10.4 Discussion

    10.4.1 Summary of behaviours. As Antaki et al. (2017) note, the service users in this study do not have resources equal to those of neuro-typical individuals. Vocabulary, syntax, prosody and epistemic status are not available to the participants with severe intellectual disabilities. Instead, people with severe intellectual disabilities rely upon non verbal communicative resources. In this study, service users appeared, or were understood, to signal disengagement from and/or resistance to an activity by averted eye gaze, body movements away from care staff and/or objects relating to the activity, movement of an assistive mobility device, body posture away from equipment needed for the activity and/or the member of care staff supporting them, vocalisations, seemingly feigning sleep, and self-harming behaviours. A noticeable absence of behaviours necessary to complete an activity (such as movement of legs and feet when using a gait trainer or gripping and moving a painting spatula during an art session) were also considered to be signs of disengagement and potential resistance.

    10.4.2 Findings related to the literature. Many of the behaviours used by the participants with severe intellectual disabilities to demonstrate resistance have also been reported to be used within the typical population for the same purpose. For example, general CA research on resistance has suggested that non-responses to previous turns may be a way of resisting the interaction (e.g. Monzoni et al., 2011; Kitzinger, 2000; Lytra, 2007; Forrester & Ramsden, 2000), as are certain non-verbal behaviours such as averted eye-gaze (Kidwell, 2006; 2009). This may highlight parallels that can be drawn between communication techniques used by people with severe intellectual disabilities and those who are typically developed. Often people who support those with (severe) intellectual disabilities report that they do not have to adapt their communication. For example, one participant in Healy & Noonan Walsh's study (2007) reported "it's not that different, I [you] talk to them the same as I talk to anyone else" (p.132). This seems somewhat unusual considering the expressive and receptive language difficulties associated with severe intellectual disabilities. However, if people with severe intellectual

disabilities are using similar non-verbal resources as those who are typically developed, such statements may begin to become more understandable.

10.4.3 Importance of the overall trajectory of the interaction. As acknowledged in chapter 6, conversation analysts often look at tiny snippets of interactions. This can allow a micro analysis of behaviours and allow researchers to break down what is happening on a turn by turn basis. Yet, such techniques can neglect the overall shape of the whole interaction which is also important (Robinson, 2012; Fitzgerald, 2017). This chapter has highlighted how important that can be. Small extracts of the example described in 10.3.2.2 (Jake leaving music with Eric) could not have encapsulated how the interaction unfolded and how his reactions and resistance to the course of action that was being promoted by the staff member were upgraded. This is a topical issue for conversation analysts and ethnomethodologists alike.

10.4.4 Following different agendas. Examples presented in this chapter suggest that at times the agendas of service users and staff members do not align. For example, in 10.3.2.2, Jake appears to want to leave the music room and move about on his scooter, whereas Eric wants Jake to remain in the room with the music session. In discussion, Eric explained that he wanted Jake to stay in the music room because of his "timetable" and that he was not "meant to be on his scooter during this time". He appears to be following institutional agendas and not enabling Jake to have his choices and decisions respected and realised. When institutional agendas are blindly adhered to without due consideration as to why they are being followed, or how following them may restrict a person's liberty, it is a concern. This is not best practice. However, it is equally as important to remember that some institutional agendas, such as providing medicine and personal care and ensuring that everyone is safe, are vital. Whilst Simon may resist having cream applied, he will also benefit from its soothing qualities. Institutional agendas are not always a bad thing but how and why they are followed should be considered. It is important that management has a clear vision of how a centre should work. Without timetables in an institutional setting for example, it would be difficult to ensure that varied experiences, both sensory and social, can be provided to help encourage interaction and to develop skills. However, it is also important that this vision takes account of the need to be flexible wherever possible and embodies proper consideration of the rights of service users. Front line staff need to appreciate that this

balance is important and have the ability and resources to depart from fixed institutional agenda where to do so would not cause detriment either to the service user or the institution. Currently such principles may not be integrated into practice.

10.4.5 Various potential functions of activities. In this chapter I have examined resistance by reference to each person's timetable of activities such as art, music, gardening and so on. In these examples, the behaviours of the service users may seem, or are responded to as if they are resisting these activities per se. However, just because a person is not engaging in a particular activity, does not mean they are fully resisting that activity or all interaction. For example, just because a person is not painting, does not mean they do not enjoy the feeling of paint on their hands, the touch of staff members manipulating their hands, being talked to, or sharing a space with another person. It is important to recognize that activities have a number of functions and that a person may resist some but not necessarily all of them.

10.4.6 Promoting physical independence. The examples in this chapter demonstrate how being able to move independently promotes choice. For example, when Jenny is able to move around during the interactive musical story session, staff understand her behaviour to mean that she may want a different musical instrument or more staff attention, something she may not have been able to express, whichever is the case, had she been in her wheelchair. Likewise, Jake's physical independence allows him to clearly demonstrate that he does not want to stay in the music session, even if that decision is not treated as legitimate by the staff member supporting him. Similarly, when Jake demonstrated that he wanted to leave the music sessions when he was supported by Baruk, Jake rocked in his wheelchair, moving it towards the door, demonstrating how physical movement was still a way to demonstrate service users' decisions even when physical movement was constrained by his wheelchair. Whilst the most obvious examples of resistance involving physical movements may include participants resisting activities by moving their whole bodies (as in the examples listed above), it also appears as if movements of specific body parts can also signal resistance. Examples include participants moving their heads away from staff members and/or stimuli, stamping their feet and lifting and stretching their arms as well as pushing staff and/or objects away. This has significant implications for those with severe intellectual disabilities who have particular problems with physical mobility as they are likely to find it considerably more

difficult to express resistance. It is also highlights the benefits of, when possible, assisting users out of their wheelchairs and enabling physical independence in different ways. Examples in this chapter include use of a specialist scooter and by providing kneepads so service users can safely move around on their knees.

10.4.7 Respect decisions. I would argue that in this chapter there are examples of people with severe intellectual disabilities making responsible decisions regarding their well-being, something that the DSM-5 claims people with people with severe intellectual disabilities cannot do (APA, 2013; Nicholson, 2017). People with severe intellectual disabilities may need additional help to make more complex decisions as they may not be able to assess all the potential associated benefits and risks, but it appears responsible to remove yourself from a situation which makes you distressed, particularly if the associated benefits and risks are limited. If the benefits and risks of any situation are not significantly additional to those that could be understood by the person with severe intellectual disabilities then their decisions and choices should be treated as legitimate. I can see no reason for example why Jake, supported by Eric, ought not to have been allowed to leave the music room.

10.4.8 Respectfully dealing with ambiguity in interaction. One of the most difficult challenges that people supporting people with severe intellectual disabilities face is when to continue, and encourage, an interaction and when to end it (Finlay et al., 2008). This is particularly difficult because the behaviours of people with severe intellectual disabilities and are often considered ambiguous (e.g. Porter et al., 2001).

Whilst at times it may appear that care staff are "pushing" an interaction, in many ways it would be easier to abandon it. Some care staff appear never to encourage interaction beyond that which is necessary to provide basic care. Just because a care staff member does not respond to seemingly resistant behaviours does not necessarily mean they are inattentive to them or that they are disrespectful of them. They may simply want to encourage communication, interaction and engagement in a range of activities, qualities that could be considered as promoting inclusion. Whilst I am not suggesting this is always completed in the most sensitive ways, such efforts, even if they fail, may not be a reflection of a lack of caring values.   Some of the care staff that may appear to be inconsiderate during snapshots of interactions presented within this chapter (and this thesis in general) also spent their days off visiting service users in hospital when they

experienced periods of ill health or would use their own money to buy equipment they thought would benefit the service users.   Despite these kind intentions, these care staff may overlook certain behaviours from service users which appear to be demonstrating resistance.   How and when to deal with this ambiguity is a question which will never have a clear answer as it is not an exact science. Further training using real-life examples, like those presented within this chapter, may benefit well-meaning care staff. It is likely that encouraging staff to attend to resistance which is upgraded or repeated could be particularly beneficial.

10.4.9 Completing activities on behalf of the service user. One thing that has been apparent in some of the examples within this chapter (e.g. Extracts 9, 10 and 13), is that staff members sometimes complete activities on behalf of the service user. In Extract 13, Saheb pushes Simon around, instead of him walking in his gait trainer. This was not uncommon. In fact, the extent to which this occurred really shocked me during my time in different centres. Within my ethnographic notes, I wrote about times when staff members made Easter bonnets for the service users during a "craft session". Yet, all but one of the service users were positioned nowhere near the staff or the table where the staff were making the bonnets. Similar things happened during a gardening session, where staff gardened, and the service users were simply left to sit in their wheelchairs relatively nearby but not so they were involved in any way. Neither could they easily observe the process. In some of the examples in this chapter, staff completing the activity are at least framing the activity as joint, at least acknowledging the service user as a potential contributor to the interaction (e.g. Extract 9).   To continue to complete an activity on behalf of a person with severe intellectual disabilities may lead to staff controlling the interaction and may be disempowering for service users.

It was this phenomenon, staff seemingly completing activities on behalf of the service users, which led to my interest in mealtime interactions, the topic of the next chapter. That is because mealtime interactions appear special. Because they necessarily rely upon being co-completed by the staff member and service user, resistance could not be ignored.

11. Mealtimes

11.1 Overview

As outlined in chapter 7, my interest in examining mealtime interactions was partly influenced by practical considerations. For example, the fact that mealtime interactions generally involve only two people and occur frequently and regularly meant that footage was easy to obtain, transcribe and analyse. This is in line with the conversation analysis principle of analysing "whatever data you can lay your hands on" (p. 71 ten Have, 2007). My interest in this topic also coincided with a renewed focus upon mealtime interactions in the dysphagia and intellectual disability literature (Robertson et al., 2016; Perez, Ball, Wagner, Clare and Holland, 2015). During the writing up stage of my PhD I took some part time lecturing work in a Language and Communications Science department, which largely catered for speech and language therapy students. Whilst working there, in discussions about my ongoing PhD work with several members of the multidisciplinary department, I began to gain a fuller appreciation of the potentially far reaching implications of research examining mealtime interactions. Though these factors influenced my ever growing interest in this area,that interest was originally fuelled by my observation that co-operation is essential between care staff and participants with severe intellectual disabilities if my participants were to eat and drink. As outlined in chapter 10, I noted that in other activities signs of resistance and/or non-participation by those with intellectual disabilities were not always fully acknowledged or responded to. By contrast, the engagement of the service user at mealtimes is absolutely essential so disengagement could not be ignored.

If a person with intellectual disabilities eats orally, (rather than using other methods to receive necessary nutrition, fluids and/or medications, such as Percutaneous Endoscopic Gastrostomy, or PEG, which allows such substances to be put directly into the stomach; NHS, 2015) and relies on mealtime support to eat, feeding and drinking activity cannot be completed without that person's participation. The person with intellectual disabilities cannot simply be a passive participant as it is essential that the behaviours of the person with intellectual disabilities and the person supporting them are coordinated and cooperative for the action of eating or drinking to be completed. A person, at the very least, needs to open their mouth for feeding or drinking to take place. Yet research

relating to how people with severe intellectual disabilities and people who provide support for them, such as care staff, manage to coordinate their behaviours during mealtimes is limited.

11.1.1 Dysphagia and mealtime support. People with intellectual disabilities often have difficulties eating and drinking. Many of these problems are related to specific swallowing difficulties, although it is worth noting that this is not always the case (Ball et al., 2012). Dysphagia, or feeding and swallowing disorder, has been defined as a "difficulty in oral preparation for the swallow or in moving a spoonful (bolus) from the mouth to the stomach" (Van der Gaag, 1996, p.181). Dysphagia is associated with intellectual disabilities, with the association seeming more pronounced in people with severe intellectual disabilities (Robertson, Chadwick, Baines, Emerson & Hatton, 2016). Dysphagia is also associated with several health problems, or medical-related risks. These include, but are not limited to, asphyxiation, or loss of oxygen, and aspiration, or inhalation of foreign contents that should not be inhaled (including food, drink, vomit, mucus and so on), all of which can lead to respiratory tract infections, choking, airway blockage, poor nutrition and/or dehydration (Helfrich-Miller et al., 1986; Wood, 1994; Samuels & Chadwick, 2006; Kennedy, McCombie, Dawes; McConnel & Dunnigan, 1997). These problems are associated with increased morbidity and mortality (Glover et al., 2014). Medical risks relating to dysphagia have been outlined in the report "Death by Indifference" (Mencap, 2007) and in the report "Understanding the Patient Safety Issues for People with Learning Difficulties" (NHS – National Patient Safety Agency, 2004). As outlined below, it is these medical risks and the strategies which are used to manage them, which receive the most attention both in the literature and from those who support people with intellectual disabilities and dysphagia during mealtime interaction. Although it is acknowledged that there are psychological and social risks, these are significantly less well documented.

Speech and language therapists provide personalised advice about how people supporting those with dysphagia, including those with intellectual disabilities, should manage mealtimes. However, as this guidance largely relates to dysphagia management and often overshadows or entirely replaces any advice about communication at mealtimes (Harding & Halai, 2009). Furthermore, those supporting people with dysphagia at mealtimes also experience barriers to implementing guidance from speech and

language therapists. Studies conducted by Chadwick et al., (2003), Crawford, Leslie and Drinnan (2007) and Charpentier, Morgan and Harding (2018) suggest that although adherence to speech and language therapy dysphagia guidelines is high, there are still areas of non-compliance. For example, carers may experience lack of training, a shortage of specialist equipment or have difficulties implementing guidelines because of the behaviour of the person they are supporting. Chadwick et al. (2003) evaluated compliance with four aspects of guidance provided by speech and language therapists: 1. Changing the consistency of food or drink 2. Physical positioning, 3. Use of equipment and 4. Support, prompting and socialising. The guidelines relating to support, prompting and socialising were the least adhered to across several settings. Chadwick et al. (2003) suggest that this may be because the guidelines relating to support, prompting and socialising are less concrete than others. For example, it is likely that guidelines relating to social aspects of an interaction are more abstract than instructions relating to the use of specialist equipment such as adapted cutlery and plate guards. Examples include responding appropriately to cues from the other person but without outlining what those cues, or appropriate responses to them, might be. Chadwick noted that guidelines about pacing and ensuring that a bolus had been swallowed before offering more food were often not followed. Interesting, Charpentier et al. (2018) noted that parents supporting children with dysphagia and intellectual disabilities were more likely to adhere to guidelines relating to communication and pacing compared to use of specialist equipment and postural management. This highlights the need for objective examples of interactional and interpersonal mealtime support for adults with intellectual disabilities and dysphagia. Robertson, Chadwick, Baines, Emerson and Hatton (2018) note the need for additional attention to be paid to mealtime interactions involving people with intellectual disabilities and dysphagia.

Crawford, Leslie and Drinnan (2007) also assessed adherence to speech and language therapists' guidelines. Their checklist covered five areas of advice relating to dysphagia support, namely 1. Utensils, 2. Positioning 3. Mealtime guidelines 4. Food preparation and 5. Direct support. Only the guidance relating to mealtime and direct support encapsulates the interactive elements of mealtimes. Crawford et al. (2007) define mealtime guidelines as "general advice for carers at mealtimes, e.g. supervision or prompting" and direct support guidelines as "hands-on recommendations for carers when

assisting clients (e.g. pacing, where to sit, how to angle a spoon, chin support)" (p. 329-330). The only interactional examples offered in these definitions are 'pacing' and 'prompting', actions that rely upon the behaviours of care staff but do not necessarily recognise the role of the person being supported in the interaction.

As further exemplified below, the social elements of mealtimes are often not given as much attention as changes to the environment, equipment or food. Here, it is important to define "social elements of mealtimes". As the Dictionary of Psychology (Reber, 1995) acknowledges, "social" is a "splendidly broad adjective which can safely be used for any situation which involves two or more conspecifics (members of the same species)" (p.728). This means that the interactional, or communicative, aspects of mealtimes, such as how care staff and service user signal to one another to co-ordinate mouthfuls, would be defined as "social" as per Reber's definition. However, during mealtimes there may also be interaction which does not relate to eating or drinking. Not all activity during any mealtime need relate to simply consuming calories. Social activity can also be understood to relate specifically to spending time with another for intrinsic reasons. Examples from mealtimes involving typically developed people could include joking, gossiping, discussing the weather and so on. The term social activity is often used to refer to recreational or fun social activity, rather than solely communicative or interactional activity, which Reber's definition is broad enough to encompass. In this chapter, for clarity, a distinction has been made between "interactional activity" and "social activity". The first relates to all communicative behaviours (including both the co-ordination of feeding and social-recreational activity) and the latter, more specifically, relates to recreational activity outside the tasks of eating or drinking. In this definition, all "social activity" is "interactive", as to engage in recreational activity outside of the tasks of eating or drinking has to involve interaction with another person.

In the study conducted by Crawford et al. (2007) carers rated "social activity" as the least important of six priorities for adults with intellectual impairments, scoring less than taking medication, eating and drinking, leisure activity, foot care, and physical activity. This supports the idea that the social elements of mealtime interactions, the fun/recreational aspects of activity, are not prioritised. Research seems to indicate that the focus is on getting the job of mealtime done. Other social, in the sense of

recreational, elements are not currently viewed as a priority or an area with important associated risks which are non-medical.

For example, Robertson et al., (2016) suggest that potential psychosocial risks which may be affected by limited interactional activity, may include a reduction in the choice and enjoyment of food and drink due to restricted diets and/or required modification of food texture or drink consistency.   The communication which does occur during mealtimes involving people with severe intellectual disabilities can tend to focus on the environment, or the process of eating and drinking, rather than creating a two-way interaction (Bailey et al., 1983; Ferm et al., 2005). This is in line with the research of Harding, Wade and Harrison (2012) which notes that research articles tend to focus on strategies that relate solely to managing dysphagia, such as food modification, body positioning or the use of specialist equipment, and tends to neglect interactional aspects of mealtimes. Harding and Halai (2009) emphasise the importance of considering the communicative behaviours during mealtime interactions involving people with complex eating and drinking needs.   Harding and Cockrill (2015), who completed research with children with dysphagia, identify the need to manage the health and emotional risks associated with eating, drinking and swallowing. It is also important to note that psychological and social risks are not necessarily unrelated to medical risks. For example, it has been suggested that if interaction relating to eating and drinking is effective during mealtimes then risks relating to swallowing are reduced (Harding & Halai, 2009; Mathisen, 2001). If a carer can effectively understand from the behaviour of the person with intellectual disabilities, for example that their mouth still contains food, the carer may wait a little while before offering more and thus prevent a harmful gagging or choking response.

Whilst neglecting to pay due attention to the interactional aspects of supported eating and drinking may give rise to medical and emotional risks, concentrating interaction solely on the task of eating or drinking undermines the opportunity for social activity which is not essential to achieve that task, such as engaging in simple chat or being playful.   This loss of opportunity has been recognised as a potential psychosocial risk relating to dysphagia (e.g. Ferm et al., 2005; Mathisen, 2001). More focus upon both the interactional and social elements of mealtimes is likely to lead to a better understanding of how to improve the enjoyment and experience of mealtime interactions

involving people with intellectual disabilities, an area which Ball et al., (2012) acknowledge needs additional research.

It appears that adopting a more holistic model of health (such as the biopsychosocial model, outlined in chapter 7 and further discussed in chapter 8) when considering mealtime support for adults with intellectual disabilities, particularly adults with severe intellectual disabilities, could provide significant additional insights. Focusing on the interactional, as well as practical, medical-related aspects of mealtime interactions could provide two important findings. First, it could uncover interactional strategies used by both staff members and people with intellectual disabilities to manage the activity of eating and drinking. This could have implications for dysphagia management. It could also add to the understanding of, and promote, social aspects of mealtime interactions, such as the initiation of jokes or games and other social activity that occurs during mealtimes but does not necessarily directly relate to the intake of food or drink.

11.1.2 Appropriateness of conversation analysis (CA). Conversation analysis provides a systematic approach to examine how social action is co-achieved. One of the benefits of using this approach is that it ensures that the behaviours of the person with severe intellectual disabilities are considered, something that has largely been neglected to date. As Harding and Halai (2009), acknowledge, it is important to try to establish how people with limited communication signal that they are ready for food or drink. It also allows examination of how care staff behave during mealtime interactions. Such a focus would allow for the interactional resources of care staff to be recognised as an important factor in dysphagia management strategy, alongside an appreciation of the practical tasks that must be completed (such as modifying food and drink, supporting a person in a particular position and using specialist equipment – Chadwick et al., 2003). One of the underlying principles of CA is that participants in a "conversation" are considered "to mutually orient to, and collaborate to achieve, orderly and meaningful communication" (p.1 Hutchby and Wooffitt, 2008). Using this approach allows for behaviours to be situated in the interaction and related to behaviours and/or turns that occur before and after it. This is an advantage over other methods, such as those involving frequency counts including partial interval recording (discussed in chapter 9).

Conversation analysis has been used to examine the sequential order of non-verbal interactions both in children (e.g. Filipi, 2009) and adults with disabilities (e.g.

Finlay, Antaki & Walton, 2008). There is also a growing body of work which uses conversation analysis to examine the communicative and social aspects of mealtime interactions (e.g. Kent, 2012; Jenkins & Hepburn, 2015). Recently research using discursive psychology, a related analytical approach, has examined expressions of pain by children with long-term health conditions in the context of family mealtimes (Jenkins & Hepburn, 2015).

The importance of improving the experience and enjoyment of mealtimes for people with intellectual disabilities has been recently acknowledged (Ball et al., 2012). The area calls out for real examples and a close examination of actual mealtime interactions.   A close examination of the micro aspects of feeding interactions should provide a clearer account of what mealtime interactions involving people with severe intellectual disabilities and carers actually look like. It should also illuminate how the action of eating or drinking by the person with severe intellectual disabilities is co-achieved and may shed light on a number of factors, such as how problems are communicated and managed.

11.1.3 Research Questions

Initially the focus of this chapter was the following three questions: How are mouthfuls co-achieved? How are these sequences of behaviours organised? How is control shared (or not)?

In exploring them, these topics were divided into smaller more precise themes. The following themes form the structure for the analysis presented below:

1.   Sequential analysis of co-achieved mouthfuls

2.   Different behaviours used by staff to demonstrate they are ready

3.   Different behaviours used by people with severe intellectual disabilities to demonstrate they are ready

4.   Interactions involving service user unreadiness

5.   Interactions involving staff unreadiness

6.   The role of eye gaze

7.   Staff and service user attuning to one another and the role of the relationship

8.   Relating mealtime behaviours to decision making capabilities

9.   Summary and conclusion

11.2 Method

My ethnographic notes were consulted, read and re-read and additional notes relating to themes and/or patterns of behaviour were made. The video footage was watched in real time. A sub-corpus of the video material was formed to contain only mealtime interactions. Of the 40 hours of general interaction data, there were 30 interactions, totalling approximately 9.5 hours of video that included eating or drinking. These videos were then catalogued and analysed with a focus on how mouthfuls were co-achieved.

The videos involved four service users and 13 members of staff. Although five participants with severe intellectual disabilities were recruited, during the course of my research one of the participants, Thomas, experienced a significant deterioration in his health and because of these complications was fitted with a PEG (Percutaneous Endoscopic Gastrostomy), a tube which goes directly into the stomach, through the abdominal wall.   Consequently, Thomas was not filmed during his mealtimes.

Almost all of the interactions were filmed during lunchtime, although there is some footage of people having drinks or jelly in the morning/early afternoon. The videos in this sub-corpus mainly capture mealtime interactions, but some also include the activities (or lack of activities) that occur immediately beforehand or afterwards.

The videos varied in length, from some short drinking interactions lasting 2 minutes for a single drink, to approximately 40 minutes of footage capturing lunch, dessert and a drink.

11.3 Sequential Analysis of Co-achieved Mouthfuls

11.3.1 Conversation analysis terminology. In many of the sequences transcribed and described below, the staff member prepares a spoon of food and puts it in a particular position relevant to the person with severe intellectual disability. The presentation of objects has been discussed elsewhere (Learner & Zimmerman, 2003) and clear evidence is provided to demonstrate that non-verbal presentations of objects can act as offers. Learner and Zimmerman refer to such offers in the context of children holding out an object towards another as an offer for it to be accepted. Originally in my own analysis, I referred to this as an "offer" but, as explained below, I soon became

uneasy with the restrictive nature of this terminology. For the activity of eating to be completed, both parties needed to be attending, willing and able. I have referred to this as "demonstrating readiness".

Because of the differing abilities of the participants with severe intellectual disabilities, the ways in which they demonstrate readiness to staff, and the ways in which staff demonstrate readiness to them, is specific to the person. However, despite the fact that participants have different communicative behaviours, the actions that these behaviours achieve appear to follow the same sequential pattern.

In observing staff and service users at mealtimes, it became clear that repeated sequences of behaviours occurred. Staff and service users have to co-ordinate their actions; it is not only important that they themselves are attending, willing and able but that they can also understand when the other is.

As outlined in chapter 6, "conversations", here understood to encapsulate both verbal and non-verbal behaviours, are ordered. Behaviours of people involved in interactions are not produced in isolation. Instead they relate to the surrounding behaviours. Interactional turns are relevant to the turns that preceded and those that will follow. Social actions occur in interactions sequentially (Stivers, 2012). The simplest example of sequential organisation in "conversation" is the adjacency pair (Sacks, 1967; Schegloff, 2007).

Adjacency pairs are pairs of conversational turns which occur next to one another, each produced by a different person (Schegloff & Sacks, 1973). Each pair has a first pair part (FPP), produced by the first person, and a second pair part (SPP), produced by the second. In talk, there are established FPP and SPP pairs, such as offers (FPP) and acceptances/declinations (SPP) and requests for action (FPP) and grants/declinations (SPP) (Schegloff, 2007).

Using the term "offer", as I had originally done, suggests that the staff member was the first person to initiate the interactional sequence of the person with severe intellectual disabilities having a mouthful of food or drink. This terminology may also imply a member of care staff should be, or is, in control of the interaction, with the staff member deciding when each mouthful is offered.

As exemplified in the Staff Unreadiness section (11.7) below, in this was not always the case. Some mouthfuls are initiated by people with severe intellectual

disabilities.   Some suggest that people supporting someone to eat should wait for the person to signal that they are ready for the next mouthful, suggesting that they may do so by looking at the person supporting them or by opening their mouths (Schwier & Stewart, 2005).   Examples of this are presented below. These behaviours might sometimes be referred to as "requests".

However, viewing these behaviours – those that may otherwise be described as offers and requests - as demonstrations of readiness, has advantages. One advantage is that demonstration of readiness is a neutral term and acknowledges the co-operative nature of the activity. Also, readiness can be demonstrated at varying levels of intensity. Whilst some demonstrations of readiness may look like requests and offers, others may be more subtle and may look more like pre-expansion sequences (Schegloff, 2007). Pre-expansion sequences are defined and exemplified in chapter 6. CA researchers invariably have to interpret data and generally categorise data in analysis by reference to established specific terms such as offer and request. In CA, approach-specific terms can be very useful. However, I suggest, that in this analysis, the use of a more inclusive and neutral label – readiness – may accommodate this ambiguity and allow for a greater degree of flexibility and more nuanced interpretation of the data where those involved have limited communicative ability.   This is in line with Pomerantz's advice to early researchers which is to ensure accurate description of whatever is happening in an interaction and not to become obsessed with applying the existing CA vocabulary if it is not suitable (Albert, 2014b).

11.3.2 Preferred sequential order of mouthfuls. As outlined in chapter 6, for some adjacency pairs, there are alternative SPPs.   If the FPP is a demonstration of readiness, then the SPP could be either a demonstration of readiness or unreadiness. In this case a second pair part that aligns with the course of action of the FPP is referred to as preferred, and SPPs that do not are dispreferred. Preference here does not refer to the psychological motives of the second speaker but to a course of action which aligns with that suggested by the first. When one person demonstrates their readiness to the other, then the preferred SPP would be for the other person to demonstrate they too are ready (attending, willing and able) as this would align with the intended course of action (of a mouthful being achieved) of the FPP.

Extracts 16, 17 and 18 below offer non-verbal examples of a person's first pair part (here, a demonstration of readiness) being responded to with a preferred second pair part (here, another demonstration of readiness), so the interaction is fairly straightforward.

In extract 16 Jamie, a man with severe intellectual disabilities, is having lunch in the dining room. Lacey, a member of care staff, is supporting him.

1	Jake	[((looks towards food 2s))=
2	Lacey	[((prepares a spoonful of food for 3s))
3	Jake	= ((dips head down and then returns gaze towards food))
4	Lacey	((moves a spoonful of food towards Jake and stops
5		approximately six inches in front of Jake's face))
6		(.)
7	Jake	((opens mouth widely))
8	Lacey	((moves spoon towards and into Jake's mouth and with her
9		other hand holds tissues slightly underneath his chin))
10	Jake	((closes mouth and eats))

Figure 35 – Extract 16 – Jake with Lacey, mouthful achieved.

Although there is no speech in this interaction, Jake and Lacey are still able to co-ordinate their behaviours so that Jake is able to eat. For this to be possible, it is essential that they are able to demonstrate to one another when they are ready. It appears that Lacey's presentation of a spoonful of food, in a particular position (in line 4) , namely at eye level, slightly to the right of Jake, demonstrates that Lacey is ready. In line 7, Jake responds to this by opening his mouth. At this point, the food is on a spoon near Jake's mouth, which he has open. It is clear that both parties are ready to co-complete the next mouthful and the actions that follow allow this to be achieved.

Extract 17 also offers a non-verbal example of a mouthful being co-achieved. In this example, Jenny, a woman with severe intellectual disabilities, and Tom, a member of care staff, are together in the dining room.. I am sitting at the table with them. Andrew, a man with mild-moderate difficulties, who is verbally fluent, is also sitting with us. Although there is some talk in this extract, it is not directed towards Jenny. Andrew is

asking Tom if he had seen a TV programme earlier in the week. However, the focus here is on the interaction between Jenny and Tom.

1	Jenny	((looks towards food clasping her hands together in front of her
2		chest))
3	Tom	((moves food around the plate, 'chopping' it with a spoon))
4	Andrew	D[¹id yo[²u watch ant n dec las- [³ (.) the other night
5	Tom	[¹ ((moves the spoon so it is immediately in front of Jenny, on
6		the right hand side of the plate. Then, turns the spoon slightly
7		towards Jenny))
8		[³((looks towards Andrew))
9	Jenny	[² ((looks up, towards Andrew and smiles then looks
10		down towards the spoonful of food and reaches for it=
11	Tom:	[N::o (.) what night was this
12		[((looks towards the spoonful of food and Jenny's hand))
13	Jenny	= ((grabs the spoon, with Tom's hand still on it, and pulls
14		towards her mouth, which she opens))
15	Tom	[((gazes towards the spoon and his and Jenny's hands as they
16		move it towards her mouth, looks to Jenny's face, quickly
17		towards Andrew and back to Jenny's face)) ((move the spoon
18		into Jenny's mouth))

Figure 36 – Extract 17 - Jenny with Tom and Andrew, mouthful achieved.

Extract 17 also illustrates how a staff member presenting a spoon in a particular position, here on the right hand side of Jenny's plate with the handle facing towards her, demonstrates that the staff member is ready to assist Jenny to take the next mouthful. This is exemplified in lines 5-7. In lines 9-10, Jenny then demonstrates her readiness. She does so first by reaching for the spoon. Once her hand is on the spoon, Tom provides hand-over-hand support to help Jenny move the spoon to her mouth which she opens. Whilst the positioning of the spoonful of food is in a different place for Jenny than it is for Jake in extract 1, both follow a similar sequential pattern. Also, as Jenny is able to move the spoon to her own mouth, with support, her sequence is slightly longer but it is still

sequentially structured based upon the back and forth of each party demonstrating their readiness to continue the actions necessary to co-achieve Jenny eating a mouthful of food.

Extract 18 involves Simon, a man with severe intellectual disabilities, and Monty, a member of care staff and Simon's keyworker. Instead of eating in the dining room , they are eating in one of the activity rooms.   Monty explained that this was partly an attempt to keep Simon calm and free from distractions as during this period Simon had begun to scratch and slap his face significantly more often, and more intensively, than he had previously. Monty also expressed that he - Monty - "liked to ring the changes". Because of Simon's tendency to slap his face and engage in other such activities, it was rare that his mouthfuls were achieved straightforwardly. However the example below demonstrates an instance when this largely occurred. Later in this chapter, I discuss the extent to which this is the case in more detail. For now, let us treat this as a straightforward example. In the video they are sitting at a small round table. Simon is in his wheelchair with a tambourine in his left hand and Monty is sitting at the table on Simon's right. Simon has limited vision.

1	Simon	[((chews from his last mouthful and bangs the tambourine
2		rhythmically 7 times in 5s))=
3	Monty	[((starts preparing the next spoonful by putting food onto
4		the spoon))
5	Simon	=((stops banging the tambourine for 2s))
6	Monty	((continues to prepare spoonful))
7		((slightly lifts spoon approximately 5cm above plate looks
8		towards and directs speech to researcher)) he gets [a good
9		appetite when he's been in ↑hy]↓dro
10	Simon	[((begins to bang the
11		tambourine again, then stops))]
12	Monty	((turns to face Simon and moves spoon to approximately 3-
13		4cm from Simon's mouth))
14	Simon	(0.4) ((opens mouth))

15   Monty   ((moves spoon into Simon's mouth))

Figure 37 – Extract 18, Simon with Monty, mouthful achieved.

In this example, both Simon and Monty attend to other things, rather than ensuring Simon eats, seconds before the mouthful is achieved. Simon is engaged in banging his tambourine, whereas Monty directs talk to the researcher. However, lines 12-15 demonstrate a clear sequential pattern. Monty demonstrates his readiness by presenting the spoon near Simon's face, (line 12-13) and after a short pause Simon then demonstrates his readiness and then eats.

11.3.3 Summary of base sequence. The extracts above demonstrate how staff and service user are able to co-achieve the necessary action of the service user eating without relying on speech. Although there is some speech in the extracts, it is not directed to the people with severe intellectual disabilities. On looking at the behaviours that immediately occur before each mouthful, it is noteworthy that, in all 3 extracts, the fundamental sequence of the interaction remains the same:-

FPP: Demonstration of readiness by the staff member

SPP: Demonstration of readiness by the service user

So far, this analysis only focuses on the base adjacency pair and not on any expansion sequences. That is, these examples do not look at any interactional turns before (pre-expansion sequences), after (post-expansion sequences), or in the middle (insertion-expansion sequences) of the base adjacency pair. Examples that could be described in these terms follow.

These examples are relatively straightforward. They demonstrate Pomerantz's principle that when one person's first pair part (here, a staff demonstration of readiness) is responded to with a preferred second pair part (here, a service user's demonstration of readiness), the interactions can be sequentially simple. As demonstrated later, when responses are dispreferred, the sequence can be less straightforward and involve additional interactional work.

11.4 Different Behaviours Used by Staff to Demonstrate They are Ready

Although interactions can look sequentially similar, the behaviours which make up the turns of the interaction sometimes differ. In this section, I examine the behaviours which staff use to demonstrate they are ready to continue with the social action of co-achieving the person with severe intellectual disabilities eating a mouthful of food.

11.4.1 Preparation of spoonful and placing it in a relevant position. As demonstrated in extracts 16-18, care staff preparing a spoonful of food and placing it in a position which is relevant to the person they are supporting can be understood as a demonstration that the staff member is ready to co-achieve the next mouthful. In these examples, the service users' responses serve as a 'next-turn-proof' that the service user understands that the action of the staff member demonstrates their readiness to co-achieve a mouthful. This is demonstrated by the service users in their next turns by orientating to the placement of the spoons, either by opening their mouths, or reaching for it.

11.4.2 Verbal and physical prompts. So far, the focus upon staff members demonstrating their readiness has, at least partly, been demonstrated by preparing a spoonful of food and placing it in a particular position, meaningful for the service user. However, even in relatively straightforward examples, sometimes such behaviours are accompanied by other behaviours. The use of words/touch can also be used to draw a person's attention to the spoon when their gaze is directed elsewhere. By doing this they demonstrate readiness but also call the other person to attention to their presentation of readiness

Extract 19 demonstrates how staff may accompany their non-verbal demonstrations with talk. A recurring example was "there you go" (line 6). In this extract, Thomas is supporting Jenny during lunch in the dining hall of Langley Way. She is in her wheelchair sitting at a round table. He is sitting on her right hand side.

1	Thomas	[((prepares spoonful of food, looking towards it, for 6.5s))]
2	Jenny	[((rubs her hands slowly, slightly looking down for 4.5s then
3		directly looks towards the plate of food))]
4	Thomas	((lifts the spoon approximately 15 cm above the right hand
5		side of the plate))

6		There [¹ya ↑[²go!
7		[² ((lightly brushes Jenny's arm with the side of
8		his hand))]
9	Jenny	[¹((moves her arm] and continues to do so towards the
10		spoon stretching out her hand, puts her hand over Thomas's
11		which is already on the spoon and pulls the spoon towards,
12		and then into her mouth))]
13	Thomas	[¹ ((watches Jenny's hand and tracks the spoon up until
14		it is in her mouth and continues to look at her while she eats))

Figure 38 – Extract 19, Thomas and Jenny, verbal and physical prompt.

Thomas demonstrates his readiness by presenting a spoon in a particular position (line 4) and by using a verbal prompt (line 6). It is also possible that the fact he lightly touches Jenny's arm in line 7 is designed to demonstrate his readiness, but it is unclear from the video whether, in this particular instance, the action is purposeful. As exemplified in later extracts, verbal prompts and use of touch are commonly used to direct the attention of the person with severe intellectual disabilities, particularly when the examples require a little more interactional work. However, at times, it appears that staff members use verbal prompts even when the interaction is relatively straightforward. This is the case in extract 19 where it is not necessary to gain Jenny's attention as she appears already to be demonstrating that she too is ready to co-complete the next mouthful. This is evidenced by the direction of her gaze in line 2 and the absence of any signs of unreadiness, such as engaging in other behaviours. This interpretation is supported by Jenny co-completing by taking the spoonful of food, once Thomas has clearly demonstrated that he is ready.

It was also noted that talk was often provided alongside the presentation of food for the first mouthful sequence of a mealtime – but not necessarily for the mouthful sequences that follow.

11.4.3. Gaze. The role of gaze is considered and discussed separately in section 11.8.

11.5 Different Behaviours Used by People with Severe Intellectual Disabilities to Demonstrate They are Ready

11.5.1 Opening their mouths. By definition this is action which occurs in every extract where the person with severe intellectual disabilities successfully consumes a mouthful of food or drink. This is clear from earlier extracts.

11.5.2 Reaching for the food or drink. As exemplified in Extract 19 Jenny reaches for the spoonful that is presented to her as part of the behavioural sequence which allows her to eat every mouthful. Another example is seen in extract 20, where Simon reaches for his drink, which has been moved, so that it is possible for him to reach it, seconds beforehand.

1	Simon	((rubs his face in general and then specifically his left eye, fairly
2		hard, with the palm of his left hand for 3s))=
3	Monty	=[[1]((lifts his hand to Simon's left hand, and guides it away from his
4		face))]
5		[[1](here now)] (.) <u>stop</u> that [[2]((lets go of Simon's hand and reaches
6		over to the bottle of the drink, which is on the other side of the
7		table to Simon, in front of the researcher, and lifts it up and places
8		it in front of Simon on the table with a tap))]
9		[[2]LOOK] ((bottle taps the table))
10		>drinks there<
11	Simon	[[2]((moves his hand up slightly and itches
12		his chin with his middle three fingers for 5s))=
13	Monty	((looks towards the food and begins to prepare another mouthful))
14	Simon	=((moves his hand towards the bottle, splays his fingers, leans
15		forward in his wheelchair slightly and picks up the drink, lifts it to
16		his mouth and drinks))

Figure 39 – Extract 20, Simon with Monty, reaching for drink

In this extract, after Monty has placed the bottle in Simon's reach, Simon does not rely upon any further action from Monty and is able to take the drink himself in line 15. Having food and drink available and easily accessible for a person with severe intellectual disabilities to take unsupported, in many ways is the ideal mealtime situation. It gives the person with severe intellectual disabilities control of whether, when, and how much they eat or drink. However, it is important to note that unfortunately this is regularly not the

case. At times, this is due to staff members not providing the opportunities that promote such choices, but can also be limited due to the service users' restricted mobility and/or visual abilities.

11.5.3 Stopping other activities. The stopping of other activity to demonstrate readiness during mealtimes is a category which is particularly (but not solely) relevant to Simon. As noted elsewhere (see chapter 5, Participants and chapter 10, Resistance), Simon often self-stimulated. During many mealtimes, (as well as at other times) Simon would slap his face and persistently hold, shake and bang objects such as a tambourine or a shaker. These behaviours became more severe and frequent over time, and became so severe and regular that Simon was eventually provided with 2:1 support for most activities including mealtimes. Simon's regular engagement in other activity during meal-times meant that one way by which he would demonstrate readiness is by stopping his other activity, usually slapping his face or banging objects.   Let us revisit Extract 18.   This interaction occurred while Simon was receiving one to one support.

1	Simon	[((chews from his last mouthful and bangs the tambourine
2		rhythmically 7 times in 5s))=
3	Monty	[((starts preparing the next spoonful by putting food onto the
4		spoon))
5	Simon	=((stops banging the tambourine for 2s))
6	Monty	((continues to prepare spoonful))
7		((slightly lifts spoon approximately 5cm above plate looks towards
8		and directs speech to researcher)) he <u>gets</u> [a good appetite when
9		he's been in ↑hy]↓dro
10	Simon	[((begins to bang the
11		tambourine again, then stops))]
12	Monty	((turns to face Simon and moves spoon to approximately 3-4cm
13		from Simon's mouth))
14	Simon	(0.4) ((opens mouth))
15	Monty	((moves spoon into Simon's mouth))

Figure 37 – Extract 18 – Simon with Monty, mouthful achieved.

In lines 1-2 Simon is clearly involved in activities which would interfere with him having another mouthful. He is banging a tambourine and is still eating his last mouthful of food activities which demonstrate his unreadiness.   In this extract, Simon pauses for a short time between his banging. The cessation, or at least break, in the activity that Simon was otherwise engaged in allows the space for a mouthful to be co-achieved. Simon could be demonstrating that he is ready for another mouthful in line 5, and Monty's comment in line 8-9 relating to Simon's increased appetite, although directed to the researcher, could be a response to Simon's demonstration of readiness – but this is impossible to know from the footage.   Whether Simon is, or is not, ready in line 5, Monty does not respond to him before Simon resumes banging his tambourine. The next time Simon stops banging his tambourine, Monty redirects his body position and gaze towards Simon, and moves the spoon towards his mouth, clearly demonstrating he is ready. Simon is also ready and demonstrates this by opening his mouth. Simon's cessation of banging in line 11, appears to trigger the back and forth demonstrations of readiness which allow him to eat.

11.5.4. Gaze. The role of gaze is another way people with severe intellectual disabilities demonstrate readiness. This is considered and discussed separately in section 11.8 of this chapter.

11.6 Examples of Staff Readiness and Service User Unreadiness

Whilst it is important to understand how people may signal that they are ready for their next mouthful, it is (at least) as important to identify behaviours which demonstrate that people are not ready for their next mouthful. I refer to this as demonstrating unreadiness.

Unreadiness, like readiness, can be demonstrated in a number of ways. Sometimes, a lack of behaviours that demonstrate readiness, such lack of as eye gaze towards the food and/or care staff, or not reaching for utensils or opening their mouths in preparation for food, may signal that a person is not ready. However, unreadiness does not only imply a lack of behaviours which demonstrate readiness. Examples also include actively turning away from the food or drink and the member of staff, pushing items away, use of facial expressions and various vocalisations. First, I present a number of transcripts which exemplify how these resources are used in interactions to display

unreadiness and consider how staff respond to them. There then follows an overview of the patterns of behaviour in these interactions.

The first example includes Simon, the service user who regularly slaps his face and/or bangs objects and Luke, a care worker. In Extract 21, Simon and Luke are sitting side by side on a rectangular table in the dining hall of Langley Way. I am on an adjacent side of the table, closest to Simon. This is Simon's first mouthful of food.

1	Simon	[((leaning and facing away from Luke, Simon slaps his face
2		continually and rhythmically 17 times in 5s))]
3	Luke	[(((prepares a spoonful of food for 5s))]
4		((reaches over and taps Simon's inner arm twice with his left arm,
5		while moving the spoonful of food up and towards Simon))=
6	Simon	=((stops slapping his face, and turns his head right, towards Luke
7		and food))
8	Luke	((moves spoon towards Simon's mouth until about 10" from
9		Simon's face slightly to his right)) (.)↑rea↓dy
10	Simon	((leans back slightly and opens his mouth))
11	Luke	((moves spoon into Simon's mouth))

Figure 40 – Extract 21, Simon unready, Luke ready.

In this example, Simon is clearly unready in line 1. Mouthfuls cannot occur while Simon engages in his self-stimulating activity. Luke orients to Simon's unreadiness using touch (line 4), then movement of the spoon (lines 5 and 8) followed by speech (line 9) to direct Simon's attention towards the mealtime. In line 6, Simon responds to Luke's touch by stopping slapping his face and turning his head towards Luke. His demonstrations of readiness continue in line 10. After Luke has moved the spoon, paused and asked Simon if he is ready, Simon changes his body position and opens his mouth.

Extract 20, involving Simon and Monty, also demonstrates how use of touch can be used during mealtimes to discourage other behaviours which may direct the attention of the person who is eating and drinking away from the task in hand. This was a commonly used technique – used regularly, but not only, in mealtime interactions. In Extract 20, line 3, Monty's physical contact supports his talk in line 5, both of which

discourage Simon's behaviours in line 1 which are likely to interfere with ensuring Simon eats and drinks. Monty's use of touch, alongside his talk and presentation of the bottle, discourages these behaviours and promotes the course of action.

Extract 22 involves Jake, a man with learning disabilities, and Luke, a support worker. Jake has been placed in a chair, with support, in his normal position in the dining hall. Luke is sitting to Jake's right, in the normal position for all care workers supporting Jake during mealtimes.

1	Luke	[((picks up a plastic cup of milkshake from the table to about 10" in front
2		of Jake at about chest height))]
3	Jake	[((looks at milkshake))]
4	Luke	Ready for some drink↑ ((gestures with drink, moving it up slightly))
5	Jake	((opens his mouth slightly))
6	Luke	Try↑ some
7	Jake	[Er:hm
8		[((moves head up slightly and back again, like a nod, smiling))
9	Luke	((stands up and moves towards Jake with tissue in one hand and the
10		drink in the other puts the tissue under his chin and the drink to his lips))
11	Jake	Urhm ((moves face quickly 90° to his right, away from Luke and drink))
12	Luke	OPP maybe not then
13		((moves drink back towards its original position on the table, away from
14		table goes to put it on the table, [as it touches the table, Luke lifts the
15		cup again, slightly off the table))
16	Jake	[((turns his face back, mouth slightly
17		open))
18	Luke	((moves the cup up to 15cm from Jake's mouth)) Ya ready now
19	Jake	((reaches out with his hand in a fist and softly pushes the drink away
20		from him))
21	Luke	>alright you don't want it< (.) we'll try upstairs then

Figure 41 – Extract 22, Jake unready, Luke ready

In this example, Jake's actions are originally ambiguous. His gaze towards the drink in line 3 could be perceived as a demonstration of readiness and his slightly open mouth

in line 5 would also support this. Yet after Luke's demonstration of readiness in line 6, Jake vocalises again, and moves away from the drink, suggesting he is not ready. Luke then withdraws the drink moving it back towards the table. In line 16, Jake's turn of his head back towards Luke and the drink could, again, be perceived as a potential act of readiness. Luke responds to this by providing the drink once again to Jake in line 18, but this time Jake's response is upgraded. He physically pushes the drink away in line 19, which is treated as a clearer response by Luke, as he verbalises expressing his understanding of Jake's behaviour and a solution to their current problem ">alright you don't want it< (.) We'll try upstairs then" in line 21.

In Extract 23 below, Jake is being supported by Lacey in his usual position in the dining hall.

1	Lacey	((presents spoon at about chest height approximately 12 inches from
2		Jake's face))
3	Jake	=U::GH ((turns head away from food and Lacey)) gh gh gh ((slightly moves
4		his head and shifts gaze towards the spoon then quickly looks down again))
5	Lacey	again? [((moves spoon side to side slightly)) h:::ello:::?]
6	Jake	[((looks up scrunches face and looks down to the floor))]
7		((slightly moves his head towards the food twice and then rolls his head
8		round and up and opens his mouth widely))
9	Lacey	((moves spoon to Jake's mouth))

Figure 42 - Extract 23 Jake originally unready with Lacey, non-withdrawal.

Here, Jake demonstrates that he is not ready for the next mouthful in a number of ways. In line 3, he vocalises, and turns away from the food. In line 6, he scrunches up his face, which staff may understand to be a negative reaction, and once again he looks away from the food and the member of care staff, both likely demonstrations of unreadiness. During this short extract, he called upon several of his interactional resources. He used his voice, facial expression, gaze and head position to demonstrate that he is not yet ready for the next mouthful.

Lacey leaves the spoon in the position she originally put it in, in line 1, throughout the extract until Jake eats. By not withdrawing the spoon, she is able to demonstrate her

readiness throughout. She waits for Jake to re-demonstrate his readiness. She does however try to encourage a demonstration of readiness, in line 5, both verbally and by "jiggling" the spoon. These behaviours appear to be in response to Jake's shift of gaze toward the spoon in line 4 which is potentially a subtle sign of readiness. However, in line 6, Jake appears unready again (he looks down to the floor), but the non-withdrawal of the spoon allows him the opportunity to be able to decide when he is ready for the mouthful, which he does in line 8 by opening his mouth.

In the next extract, which is taken from the same interaction as above – Lacey responds to Jake's demonstration of unreadiness differently.

1	Lacey	((presents spoon at about chest height approximately 6 inches from
2		Jake's face))
3	Jake	°meh° .HHHHH ((turns face 90° towards the right, away from Lacey
4		and the food))=
5	Lacey	((pulls spoon back so it now near her own face and looks towards
6		Jake))
7		(2.0s)
8	Jake	U:GH ((begins rocking slightly for 2s moves head around and then
9		down)) ehmm ((looks up and opens mouth))
10	Lacey	(1.5s) ok↑ay↓ [((moves spoon towards mouth))]
11	Jake	[((opens mouth wider))]
12	Lacey	((moves spoon into Jake's mouth))

Figure 43 – Extract 24 – Jake originally unready with Lacey, withdrawal

Lacey positions the spoon in approximately the same place as in the earlier extract. Jake demonstrates his unreadiness in line 3 including a loud, pronounced inbreath suggesting that he may have difficulty breathing and/or swallowing. Jake has a condition which means he may stop breathing at any time so this a particular risk to him. He also turns away. Lacey retracts the spoon, does not seek a demonstration of readiness from Jake. Instead she looks towards him and waits (line 5-6). Jake then has the opportunity and time to demonstrate he is ready again, which he does in line 9 by moving his head back around to face Lacey and opening his mouth. Lacey asks Jake if he is okay in

line 10, and moves the spoon towards him. Jake upgrades his readiness by opening his mouth wider before he receives the mouthful.

In both of the extracts above, although she uses different strategies, Lacey demonstrates the importance of waiting for Jake to be in a position where he is able, attending and willing to demonstrate his readiness. In contrast, Extract 25 below describes an interaction where the staff member, Elvis takes a different approach with Jake, which is less successful in promoting Jake's eating.

Elvis is a relatively new care worker, having considerably less experience than most of the other care staff who participated in this project. This example is taken from the beginning of Jake's lunch. He has not yet had a mouthful. He was brought down to an almost empty dining room and left while Elvis sorted out many of the things needed for Jake's lunch. This took Elvis a considerable amount of time as he ended up distracted by additional tasks involving other staff members and service users. During this period of waiting, Jake's mood appeared to change markedly. He entered the room smiling, rocking softly and lightly vocalising but after being left for over 10 minutes, he was rocking heavily, biting his hand and making louder and longer vocalisations that were more similar to screams. He also thrashed about in his wheelchair. Others, including myself, attended to Jake because he seemed so distressed and his behaviours became less extreme. Elvis then returned and continued the necessary preparation, including positioning Jake. Within a few minutes, when Elvis went across the dining hall to collect cutlery, I informed him about Jake's behaviour whilst he was away. The extract below includes the first mouthful Jake had of his lunch.

1	Elvis	((presents food to the left side of [Jake's face about 8" away and
2		then holds Jake's elbow))
3		[this way Jay
4	Jake	[((looks to up and to the left, towards Elvis and the food, looks away
5		and down and lifts arm and moves his elbow around in a circle))=
6	Elvis	=((lets go of Jake's elbow))
7		Ja::ke, (.) Jake, how about that
8	Jake	=((looks right[away from Elvis, and shakes head slightly]))

9	Elvis	[ja::ake] (2.0) ja::ke,
10	Jake	((shakes head slightly))
11	Elvis	((repositions seat))
12		((touches Jake's wrist)) Comeon
13	Jake	((looks left away from Elvis and food))
14	Elvis	>↑Jake<
15	Jake	[((looks around for 4s, slightly moving his face back away from the
16		spoon))]
17	Elvis	[((follows Jake's movements with the spoon))]
18		°are you eating?°
19		>Ere are<
20	Jake	((moves head to the left))
21	Elvis	((follows Jake's mouth with spoon))
22	Jake	[((continues to move his face around, moving it away from the
23		spoon for 8s))]
24	Elvis	[((follows Jake's movements with the spoon approximately 5" from
25		Jake's mouth))]
26		((silly voice)) .>Jake<
27	Jake	[((moves head around for 9s))]
28	Elvis	[((follows Jake's mouth with spoon))]
29		Food
30	Jake	[((moves head round for 8s))]
31	Elvis	[((follows Jake's mouth with spoon))]
32	Jake	((smile/wince))m:mgh
33	Elvis	((puts food down))
34		(4.5)
35	Elvis	((picks up food again))
36		[¹Jake]
37		[¹((touches wrist))]
38	Jake	[²((moves head around for 6s))]
39	Elvis	[²((follows Jake's mouth with spoon))]

40   Ja:ake

41   Jake   ((opens mouth))

42   Elvis   ((puts spoon in mouth))

Figure 44 – Extract 25, Jake unready, Elvis seeks readiness.

As demonstrated by the length of the transcript, a lot happens in this example. Despite the various ways Elvis attempts to elicit a demonstration of readiness from Jake, Jake demonstrates his unreadiness throughout. Jake does so not only by not opening his mouth, but also by diverting his gaze (lines 4-5 and 13), resisting physical touch (line 5) and moving his face away from the food that is being presented throughout. Elvis does not treat these signs of unreadiness as legitimate until line 33, where he puts the spoon down and waits for a moment. He actively seeks a demonstration of readiness from Jake by use of verbal prompts as well as use of touch (lines 2, 3 12, 14, and 37) and following Jake's mouth with the spoon throughout.

The talk in this extract is clearly designed to encourage Jake's demonstration of readiness. For example, Elvis uses Jake's name, nine times in this short interaction. His speech is often animated, a technique often used with infants and people with intellectual disabilities (see Nind & Hewett, 2001). The use of the term "come on" in line 12 which in English is used "when encouraging someone to do something or to hurry up or when one feels that someone is wrong or foolish" (OED, 2018).

Whilst some of these strategies have been used in other examples in this chapter, this extract looks very different. The main difference is the lack of time and space Elvis allows between demonstrating his own readiness and his seeking such a demonstration from Jake. A further difference is the sheer number of demonstrations in a short time. Actions in this example do not adhere to the centre's guidelines for staff supporting Jake which set out that staff should not follow his face if he turns away and that staff should wait to "re-offer" food if Jake refuses. The guidelines also suggest that he should not be taken to the dining hall long before his food is ready as "he does not like to wait for his food".

The reason Jake is unready is unclear. He eats his food, but many of the mouthful sequences look similar to this one. Whether he is withholding his readiness as a protest

about having been left in the dining room, because he is experiencing emotions which interfere with a desire to eat or interact, because he would prefer to be supported by another member of staff or because is not actually hungry and is only eating because of the constant, strong encouragement to do so, is unfortunately not possible to determine.

Although Jake finishes the rest of his meal, Elvis and Jake are generally not well synchronised. Elvis regularly offers Jake food when he has not finished his previous mouthful. The extract below relates to one of these times.

Immediately before the start of Extract 26 transcript Jake has been turning his head away from the spoon which, as in Extract 25, Elvis constantly presents close to his mouth, following Jake's movements with it. Elvis is using the strategies he used in Extract 25 (such as using Jake's name) but Jake is still not positively responding to them. Jake also makes some low vocalisations and lets out a large amount of saliva from his mouth, which Elvis then wipes. He stops presenting the spoon as he reaches for tissue.

1	Elvis	[Come comeon jake]
2		[((presents spoon again 2" from Jake's mouth))]
3	Jake	((moves his face away from the spoon, moving backwards))
4	Elvis	↑Ja↓ke
5	Jake	((lifts arm with hand in a fist and pushes the spoon away with his
6		wrist – it hits his nose and leaves some food on the tip of it))
7	Elvis	((brings the spoon back to be in line with the centre of Jake's face
8		but this time approximately 10" away))
9		((wipes Jake's nose with the tissue then presents the food
10		approximately 3" from Jake's mouth))
11	Jake	((turns his head 90°))
12	Elvis	((moves the spoon so it is slightly to the right of Jake's face))
13	Jake	((opens his mouth, as he does so a large "bubble" of a mixture of
14		now softened food and saliva forms around his lips until he opens it
15		wide enough that it "pops"))
16	Elvis	((places the food into Jake's mouth))

Figure 45 – Extract 26, Jake unready with Elvis.

Here, Jake first demonstrates unreadiness by moving his face away from the spoon (line 3) and then upgrading it , by using his hand to push the food away (line 5). When Jake does open his mouth (line 13), it is clear that he has been breaking down food, which is still visible in his mouth. It is possible the saliva that comes out of his mouth moments before this extract was produced to help swallow the food fully. Yet, instead of providing Jake with more time, or perhaps offering him a drink, Elvis continues with the mouthful sequence (line 16).

I observed staff offering food when service users still had food in their mouths more often than I had expected. A further example of this is provided below.

This extract involves Simon, the participant with limited vision, who often engaged in slapping and banging behaviours and Eric, a care worker. They are in the dining room and Eric has his arm around Simon's neck and his hand on his wrist/hand. This is to discourage the slapping behaviours. Like the other examples in this chapter this footage was captured before Simon received 2:1 support. Before the start of this extract Simon and Eric have completed a mouthful sequence and Simon is still eating.

1	Simon	((has food on his lip, kicks under the table, stops chewing))
2	Eric	((gently rubs Simon's hand/wrist))
3	Simon	((chews slightly open mouthed from his last mouthful))=
4	Eric	((begins to move a spoonful of food towards Simon's mouth))
5	Simon	=((continues to chew))=
6	Eric	((when the spoon is approximately 50 cm from Simon's face some
7		food falls off it. At approximately 5 cm a second piece falls off.
8		Upon the second piece falling Eric looks down and withdraws the
9		spoon back towards the plate [then moves the spoon containing food
10		back towards Simon's mouth until approximately 5 cm away and then
11		returns it to the plate))]
12	Simon	=[[(moves his tongue to his inner lip and
13		creates a clicking noise sounds as if it is coming from the back of his
14		mouth))]

15	Eric	[((brings the spoon back to approximately 10" away from Simon's
16		face then returns it to the plate, scraping food from the bottom of it
17		on the plate))
18	Simon	=[((creates the clicking noise twice then he moves his mouth slightly,
19		bringing his upper lip slightly over his lower then appears to be
20		moving food in his mouth and swallowing it))
21	Eric	((brings the spoon back to Simon's face and touches his lip with the
22		food))
23	Simon	((opens his mouth))
24	Eric	((puts spoon into Simon's mouth))

Figure 46 – Extract 27, Simon unready with Eric

In Extract 27, Simon is not ready for the next mouthful because he is still eating the last. It is possible that Eric notices this in line 8-9, and it is the reason why he withdraws the spoon, but it appears more likely he does so because of the food falling off the bottom of the spoon. He reissues his demonstration of readiness but again withdraws the spoon, presumably because he recognises that Simon is not ready by the movements and sounds he is making relating to eating and swallowing. In line 18, Simon has food below his lower lip, part of which he appears to add to the food in his mouth. Once Simon has finished and swallowed, Eric brings the food back to Simon's mouth, this time touching his lip with it, which Simon responds to by opening his mouth and completing the mouthful sequence.

The next example shows a time when Patrick, a service user, uses talk. He has limited verbal communication skills but one of his utterances is "OH NI:CE" which he uses to show he likes or enjoys something. He also enjoys proto conversations, that is non-verbal turn taking interactions that have some of the features of a conversation without formal language.

Patrick is in his wheelchair and Jose is sitting on a chair. They are neither face to face nor side by side. Instead they are sitting at an angle to one another. This extract involves Patrick's first and second mouthfuls of food at this mealtime.

1	Patrick	↑Erm nn >diddy ↑lat-↓di-↓lat< urm:m (.5) eh? (.) °nnn°
2		(1.5)
3	Jose	[(((lifts up his head from looking down, towards the food, to look
4		at Patrick))]
5		[(((moves the spoon from the plate towards Patrick's mouth))
6		[(((when the spoon is about shoulder height)) ((Let's [go Patrick))]
7	Patrick	[(((opens his
8		mouth))
9	Jose	((moves spoon into Patrick's mouth))
10	Patrick	((closes mouth and takes food))=
11	Jose	((moves the spoon out of his mouth and returns it to the plate))
12		((m::m))
13	Patrick	=[(((moves and swallows the food in his mouth))]
14	Jose	[(((prepares another spoonful of food and lifts it towards Patrick's
15		mouth))]
16	Patrick	.HH OOH NI-=
17	Jose	=((puts spoon into Patrick's open mouth))
18		(kay) you like it

Figure 47 – Extract 28, Patrick vocalises with Jose.

This extract starts with Patrick vocalising in an animated way in line 1, which does not appear to be responded to directly by Jose. The mouthful sequence from lines 3 to 11 is fairly straightforward, and both parties demonstrate readiness to the other, Jose by shifting his gaze towards Patrick, movement of the spoon and providing a verbal prompt (lines 3-6) and Patrick by opening his mouth in line 7. His gaze is also directed towards Jose throughout.

Patrick appears unready in the 2nd mouthful sequence. In line 16, Patrick takes a sharp, loud inbreath and utters "OOH NI-" before he is cut off by Jose placing a spoonful of food into his mouth. Whether Patrick was trying to say "OH NI::CE" to the taste of the first mouthful, or the upcoming arrival of the second, he is clearly enjoying the food and does not react in a negative way to the spoonful of food being put into his mouth.

Nevertheless, being part way through an unfinished utterance definitely suggests that he was not demonstrating his readiness in line 16.   This extract clearly demonstrates how getting the job of eating done is given priority over social activity that may occur at mealtimes. Patrick's initiations in line 1 and line 16 are ignored. Noticeably shortly after the end of the transcript Patrick starts to cough. It could be suggested that had Jose responded to Patrick's attempts to be social then the mealtime would have been slower paced and this may have been avoided.

 As with the previous example, the next extract involves a service user who has their mouth open for a reason other than ating, who nonetheless still receives a mouthful of food. Extract 29 was filmed when Simon was provided 2:1 support at mealtimes. Elvis, a care worker, is sitting on Simon's right and is mainly trying to control any potentially problematic behaviours such as slapping. Saheb is sitting on Simon's left and is mainly providing the prepared spoonfuls of food. They are all in the dining room.

1	Simon	[((has bottle in his hand and is drinking from it and rocking back and
2		forth))]=
3	Saheb	[((takes Simon's medication out of its bottle and places it onto the
4		plate))]
5	Elvis	=[((moves his hand to Simon's holding the bottle and tries to move
6		his hand away from his mouth)) don't do <u>too</u> much (.) you're gonna
7		take too much in (.)]=
8	Simon	[((splays the fingers of his free right hand, continues to drink,
9		resisting Elvis's attempts to move his left hand by keeping the bottle
10		to his mouth))]
11	Saheb	[((begins to prepare a spoonful of food with Simon's medication in
12		it))]
13	Elvis	=[(adv::ice) Simon (.) >↑<u>Simon</u>< (.) (advice)]=
14		[((tries to pull the bottle down away from Simon's mouth))]
15	Simon	[((continues to hold the bottle, drinking from it, resisting Elvis's
16		attempts to move it away from his mouth))]

17	Elvis	=°just have a rest° ((successfully moves Simon's hand, with the
18		bottle in it, to Simon's shoulder)) (just for a min)
19	Simon	[((opens his mouth and starts to lift the bottle to it get to in 1" of his
20		mouth))]
21	Saheb	[((moves the prepped spoonful of food with medication on it
22		towards Simon's mouth until approximately 2" away))]
23	Elvis	Hang on ((moves Simon's hand and bottle down to his elbow))
24	Saheb	((puts the spoonful of food into Simon's open mouth))

Figure 48 – Extract 29 – Simon with Elvis and Saheb.

At the beginning of Extract 29 Simon has his own bottle and is in control of how and when he drinks. In lines 5-7, Elvis, encourages Simon to stop drinking, seemingly concerned about the rate at which he is consuming the drink. Elvis attempts to stop Simon from drinking by trying to move the bottle and by using Simon's name, directives and other verbal prompts (lines 5-7, 13-14, 17-18). Simon resists this by splaying his fingers, not moving the bottle away from his mouth, and trying to put it back when it is finally moved (lines 8-10,, 15-16, 19-20). When attempting to put the bottle in his mouth, Simon necessarily has to open his mouth (line 19). Although the bottle is very close to his mouth, Saheb has also moved a spoonful of food very close (line 21-22). The two competing courses of action are clear in the anonymised picture taken from this extract in Figure 49, Picture 4.

Simon is trying to drink whilst Saheb and Elvis want him to eat. Elvis then moves Simon's hand (and the drink) in line 23, allowing Saheb to place the food into Simon's open mouth (line 24).   Although this proved possible, that was not why Simon opened his mouth.

Figure 49 - Picture 5. Simon, Saheb and Elvis at lunch. Red circles added to highlight the competing courses of action of Saheb bringing a mouthful of food to Simon's mouth while Simon moves a bottle towards it.

11.6.1 Summary of Section 11.6

11.6.1.1 Behaviours used by service users to demonstrate unreadiness. The extracts in this section show that when people with severe intellectual disabilities are not ready for their next mouthful of food or drink, they are able to demonstrate that, in spite of their limited communication methods. In fact, a wide range of behaviours were used to display unreadiness. These included: use of gaze, face position, facial expression, body position and posture, vocalisations, following other courses of action and involuntary actions such as difficulties breathing or swallowing. A lack of behaviours, such as not reaching for the spoon, failing to grab or pull the spoon towards them also demonstrated unreadiness. It is important to recognise that not all of these behaviours are necessarily available to all participants in equal measure. For example, Simon's limited vision affects his gaze. It is also noteworthy that these behaviours did not always occur in isolation. Often unreadiness was demonstrated by a number of behaviours occurring within the same turn. Finally, behaviours which signal unreadiness are not always equal. This is illustrated in the sub-section below, upgraded unreadiness.

11.6.1.2 Upgraded unreadiness. The level to which a person may demonstrate their unreadiness in an interaction can vary in a single interaction.   Jake, for example, upgraded his unreadiness regularly simply turning away from food or drink in the first instance but then moving on to pushing it away if his unreadiness continued. Two extracts in this section capture him doing exactly that (Extracts 22 and 26).

The ability to express themselves more or less forcefully may allow service users to express a range of responses. For example, rather than a simple "yes" or "no", an upgraded response may imply complete distaste. Likewise, knowing that a person has the ability to upgrade their response may encourage staff not to abandon the interaction. Where this upgrading does not occur, this may allow some flexibility in ambiguous situations. However, for such an approach to be effective, all staff would need to respond consistently to the upgraded behaviours, which was not always the case in my examples (as exemplified in Extract 22 and 26).

11.6.1.3 Behaviours used by staff to promote demonstrations of readiness. The behaviours used by staff to promote demonstrations of readiness in the sub-corpus included: gaze towards the service user, use of names, touching the service user, use of directives, movement of the spoon and verbal encouragement.

11.6.1.4 Competing courses of action. As demonstrated in Extracts 21, 27, 28 and 29 sometimes the staff members' and service users' courses of action were not aligned, that is, they were trying to do different things. Examples presented in this section include service users trying to talk, slap, bang a tambourine, drink and finish their previous mouthful when being presented with a spoonful of food.   Such misalignment was dealt with in different ways in different interactions.

In some examples, the course of action that the service user was trying to complete, namely trying to talk or drink, involved opening their mouth. On occasion, members of staff used this opportunity to place a spoonful of food inside their mouth. Two such examples have been presented here (Extracts 28 and 29). Such examples impose the will of the staff member, without due consideration for the preference of the service user. The institutional goal to feed the service user is given precedence over the decisions and choices made by the service user. In other extracts, we can see that a little patience enables the choices and decisions of the service user to be carried out and the institutional goal met. Examples demonstrated staff members waiting for the service user

to complete, or have a break from, their course of action, before attempting to start a mouthful sequence. Extracts 18 and 23 are two examples of this.

11.6.1.5 Staff responses to service user unreadiness in a mouthful sequence.

Once a staff member has already demonstrated they are ready by presenting a spoon in a particular position there are three things they can do in response to a demonstration of unreadiness. These are: 1) to withdraw the spoon 2) to leave the spoon in position 3) to use the spoon to seek a demonstration of readiness by, for example, following head movements away from the food (as in Extract 25).

I would argue that option 3, to use the spoon to seek a demonstration of readiness, is the least desirable response. Without providing the service user with time or space for their unready state to change, such behaviours could lead to coercion. Options 1) withdrawing the spoon, and 2) leaving the spoon in position, both appear to be appropriate responses to service user unreadiness. When each is used seems to depend, at least to some extent, on the circumstances of the service user unreadiness. Leaving the spoon in position allows for a continued demonstration of readiness, which gives the service user more control in the interaction as they do not have to re-elicit the staff member's demonstration. However, withdrawal tended to be used when there was a medical risk, such as a participant coughing or having difficulty breathing or swallowing.

11.7 Examples of Service User Readiness and Staff Unreadiness

11.7.1 Service users' demonstrations of readiness as first pair parts. As well as responding to the readiness of the care worker, all of the participants with severe intellectual disabilities, with the exception of Simon, sometimes used their behaviours to demonstrate readiness before a spoonful of food was presented. Their behaviours that *usually* form the second pair part of the base adjacency pair (those that follow the staff member's turn of presenting a spoonful of food) were used by the service user before the spoon was presented to them . The service user's behaviour on these occasions can become the first pair part, with the second pair part being the staff member's response. Simon probably did not use this strategy as he was mainly engaging in other behaviours during mealtimes and needed encouragement to focus upon eating and drinking. This would make him considerably less likely to initiate the mouthful sequences. Extracts involving other service users appear below.

11.7.1.1 Jake opening his mouth as a first pair part.

Extract 30 involves Jake, a man with learning disabilities, and Luke, a support worker.   Jake has been placed in a chair, with support, in his normal position in the dining hall. Luke is sitting to Jake's right, in the normal position for all care-workers supporting Jake during mealtimes.

1   Luke: ((picks up the roll[of tissue and starts rolling it out))=

2   Jake: [((looks at tissue 3.2, looks around the room

3   2.5, back towards tissue/Luke/food 1.5, looks around again 4.0))

4   .h<u>hhh</u>

5   Luke: <u>thats</u> it[Jake, (.8) wont be long   =((still rolling tissue))

6   Jake: [((opens mouth widely for [3].5))

7   Luke: [↑<u>sor</u>↓<u>ry</u> ↓<u>mate</u> you're gonna

8   have'ta hold on. (.)><u>one</u> sec<. i'm getting some tissue]

9   ((fills the spoon with food))

10   ere are (.) you ready then? ((holds spoon by plate))

11   Jake: er:rgh ((smiles)) ((opens mouth))

12   Luke   ((puts food into Jake's mouth and then wipes it))

Figure 50 – Extract 30, Jake ready, Luke unready.

In this extract, Luke and Jake are not ready at the same time. In lines 1 and 5, Luke is otherwise engaged in preparing tissue to use while supporting Jake during lunch. As further explored in the next section, Jake's use of gaze in line 3 could be seen as an initiation of the activity, (see Filipi, 2009 for examples of how pre-verbal toddlers use gaze to initiate engagement), but Luke does not respond until Jake's outbreath in line 4. After this, in line 5, Luke addresses Jake verbally, acknowledging the delay in producing his turn in the sequential routine. After Luke attends to Jake and provides him with a verbal response, Jake clearly demonstrates his readiness by opening his mouth widely in line 6. In line 7, Luke apologises to Jake, and offers an account as to why he is not engaging in the behavioural sequence they have established.

Jake's behaviours during this extract cannot unambiguously be interpreted as either a request or a complaint. It could be argued that Jake is simply anticipating the

next mouthful. This would, however, still be demonstrating Jake's readiness even if his actions were not designed for the recipient, Luke. Jake's more subtle behaviours (in lines 3 and 4), appear to motivate Luke to demonstrate his understanding of Jake's behaviour and treat the situation as a complainable one (Schegloff, 2005) and Luke's speech in line 5 orientates to the delay when the joint course of action cannot continue. When Jake opens his mouth in line 6, his readiness to continue with the course of action is clear. Luke does not provide Jake with the preferred response of demonstrating his readiness too, as he has been otherwise engaged.   Luke's response in line 7 clearly marks that his response is dispreferred in the way the turn is designed (Schegloff, 2007). He provides Jake with an apology, [SORRY MATE], an account of what needs to happen for the course of activity to continue, with an indication of how long that will be, [ya have to hold on (.) one sec], and an account as to why that is the case [I'm getting some tissue] (lines 7-8).

Examples of Jake opening his mouth, demonstrating his readiness for the next mouthful, occurred several times during the mealtime interactions I captured. They were not always noticed by staff. This is not to suggest that the staff members were necessarily being negligent or not attending to the task in hand. Sometimes such cues were missed because the staff member's gaze was necessarily elsewhere whilst completing a mealtime related task. Extract 31, presented below demonstrates this.

In Extract 31, Bako is supporting Jake in his normal seat in the dining hall at Langley Way. He has just helped Jake into his apron and his seat and has already collected Jake's cooked meal. Jake and Bako are sitting face to face and the plate of food is in between them, on a table to Jake's left.

1	Bako	[¹Jake (.) you having[²beef] [³(.) and er] (.) mash (.) and (.5) er
2		veggie]
3		[¹((starts "chopping" the food with the spoon))]=
4		((looks towards Jake from ¹ until ² then shifts his gaze downwards
5		towards the food where it remains))
6		[²((points to the beef))
7	Jake	[³((looks towards the food opens his
8		mouth widely then closes it again))]

9		[((slightly rocks softly slightly, smiling)) °er:rmh°]
10	Bako	= ((continues to move the food and prepare a spoonful, looking
11		down towards the plate))=
12	Jake	((looks forwards and opens his mouth widely for 3s and then closes
13		it)) (.) ((looks forward and opens his mouth widely again for 2.5s))
14	Bako	= ((continues to prepare the food then reaches across the table for
15		the tissue))
16		((shifts gaze towards Jake))
17		okay Jake (.) ((lifts spoon to up to approximately chest height,
18		approximately 12" away from Jake)) beef now
19	Jake	((Jake opens his mouth widely))
20	Bako	((moves spoon into Jake's mouth while moving tissue with his open
21		hand underneath his chin))

Figure 51 – Extract 31, Jake ready, Bako unready

In this example, Bako starts by telling Jake about what he has for lunch. He does so verbally (in line 1), but also provides non-verbal cues by his shift in gaze in line 4 and pointing to the food in line 6. Jake responds to this by opening his mouth, before quickly closing it again (line 7-8). This goes unnoticed by Bako, as he is otherwise engaged in further preparation for the meal until he shifts his gaze towards Jake in line 16. During the time that Bako's gaze is directed elsewhere, Jake opens his mouth twice more, these times leaving it open for significantly longer (lines 12-13).

There are a few possible explanations for Jake's behaviour. It could be that Bako's behaviours in lines 1-6, his speech (which Jake has limited understanding of), gaze shift and pointing to the food appear to Jake as demonstrations of his readiness. He would not be entirely wrong to assume this. He does eat a short time after. However, at that moment, Bako is not entirely ready. Understanding the subtle differences between workers' behaviours that indicate food will follow immediately versus those that signal it will follow soon after, particularly when similar cues are used, may be beyond Jake's capabilities.

Alternatively, Jake may want the food now. He seems happy, almost mildly excited, in the moments before this extract, as well as throughout, occasionally giving

quiet seemingly happy vocalisations, smiling and gently rocking himself as in line 8. It could be that Jake is hungry, perhaps enjoying the smell of the dining hall, and simply wants to eat. Finally, it could be that Jake knows that opening his mouth is something that moves the mealtime interactions on. Even if Jake understands that Bako is trying to show him what he is going to eat, because of Jake's his limited communication repertoire it is for an observer to be certain about the meaning of his response.

Regardless of whether Jake opens his mouth because of a misinterpretation of Bako's behaviours or whether it is designed to act as a FPP of the mouthful sequence or a positive response to what Bako is showing him, Jake clearly demonstrates he is ready at a time when Bako is not. Unlike the extract above, these behaviours are not noticed or attended to by the staff member. This is not to suggest that Bako would not respond to Jake opening his mouth before food is presented to him. He does exactly that when he notices Jake's behaviour later in the same mealtime. To ensure that this example is easy to follow and understand – I have presented it below in prose.

Bako prepares the next spoonful of food for Jake but a piece of beef is hanging off the spoon. He tries to remedy this by flicking his wrist twice to move the beef fully onto the spoon. Instead, this causes the whole contents of the spoon to fall back onto the plate. His gaze remains directed towards the plate, instead of Jake, as he begins to re-prepare the spoon. At this point, the point at which if the spoon had been filled trouble-free Bako would have presented it to Jake, Jake opens his mouth and leaves it open for 2.5 seconds. Bako originally does not notice as he is trying to ensure the beef is properly on the spoon, but looks up and sees Jake's open mouth. He immediately lifts the spoon, despite the fact , as before that another piece of beef is hanging off the side of the spoon. He hurriedly moves the spoon into Jake's mouth, angling it slightly to ensure all the food enters his mouth.

Patrick also opens his mouth as a FPP of the base adjacency pair in the same way.

11.7.1.2 Jenny reaching for her spoon as a first pair part.

Extract 32 involves Jenny, a service user and Thomas, a member of care staff. Jenny is sitting where she usually sits in the dining hall of Langley Way - in her wheelchair sitting at a round table. He is sitting on her right hand side.

1	Thomas	[(((looks towards the plate of food, preparing another spoonful))]=
2	Jenny	[((continues to eat the previous mouthful then moves her hand
3		towards the plate and drops it down under the table))]
4	Thomas	=((continues to prepare the spoonful, ensuring the medication is
5		well mixed in the spoonful))
6	Jenny	((reaches out her arm towards the spoon reaching past Thomas'
7		face))=
8	Thomas	[(((looks up towards Jenny], smiles slightly))
9	Jenny	=[(((continues to reach for the spoon, puts her hand around it, with
10		tom's hand also on it she [pulls it towards] and into her mouth))][2]
11	Thomas	[(((tracks the movement of the spoon))]
12		[(°go on°)]
13		((leans around their arms and the spoon to look at the spoon
14		entering Jenny's mouth))

Figure 52 – Extract 32, Jenny ready with Tom.

Although Thomas has not presented the spoon to Jenny, he has put food onto the spoon in lines 1 and 4. Jenny reaches for and grabs the spoon in lines 6 and 9. Thomas, who acknowledges this by looking towards Jenny and smiling (in line 8) allows the mouthful sequence to continue by not resisting Jenny's behaviours and provides a verbal go-ahead in line 12.

11.7.1.3 Salivating. Conversation analysts are usually concerned with intentional behaviour which is designed for the recipients of it. Salivation does not fall into this category and is normally involuntary and unintentional (and by definition is not designed for a recipient). It may, therefore, appear unusual to suggest such a behaviour demonstrates readiness to complete a course of action – namely the behaviours necessary for the person to eat. However, staff members attend to such behaviours as if they demonstrate that a person is hungry, demonstrating their likely readiness for a mouthful of food.

Whilst out at the Chinese restaurant (during the same mealtime as detailed in extract #), it is clear from the video footage that Jenny is salivating more than usual. Emma, a member of care staff, talks about this. She utters:

Corr! and she's getting hungry ((turns head and shift eye gaze to Jenny's face))

AREN'T YOU DARLING (.) Jenny's [getting hungry so she's saliVATing a lot more

First, Emma utters "Cor", a term which expresses surprise or alarm (Oxford English Dictionary, 2018), and then states that Jenny's hungry. Emma then directs her talk and gaze towards Jenny, speaking louder and with more emphasis, before she verbalises her understanding of Jenny's increased salivating as demonstrating she is hungry.   Here, Emma's epistemic stance is high. She appears to have no doubt that Jenny's salivating indicates her hunger.

11.7.2 Staff unreadiness due to safety of service user. The extract below is taken from the same mealtime in the Chinese restaurant.

1	Jenny	[(((chews the food in her mouth from her previous mouthful))]=
2	Emma	[(((has a prepared spoonful of food and shakes it slightly to remove
3		some of the noodles from it and holds it slightly over the plate then
4		looks towards Jenny and waits))]
5	Jenny	=[(((continues to eat and is looking down slightly towards the food
6		then leans forward [and moves are arm towards the spoon, opening
7		her hand))]
8	Emma	[(((dips head slightly to see Jenny's mouth))]
9	Jenny	((reaches for the spoon and places her hand over Emma's while she
10		is still eating – there is also food around her mouth))=
11	Emma	that okay? ((moves tissue to Jenny's mouth)) >°got something
12		there°< [let me just check]
13		[(((moves the spoon back down to the plate – out of Jenny's hand))]
14	Jenny	((continues to move food around her mouth and her hand back to
15		over Emma's on the spoon))
16	Emma	(bit) in ther- [that's it (.) clear!

17		[((looks towards spoon and tracks it as it moves))
18	Jenny	[((pulls spoon towards and into her mouth, with
19		Emma's hand underneath her own))

Figure 53 – Extract 33, Jenny with Emma in restaurant.

As noted earlier, this was a mealtime where Jenny was perceived by staff members to be exceptionally hungry. She was also left waiting for her food. When she did receive her food, she and Emma completed mouthful sequences with relative ease and synchronisation. The mouthful sequences were relatively straightforward. In this example Jenny demonstrates she is ready by looking towards, reaching for and grabbing the spoon (lines 5-7 and line 9). Yet she has not finished eating her previous mouthful (line 10). Emma's demonstrations of unreadiness lines 11-13 orient to the fact that Jenny has not finished eating her previous mouthful.

This extract demonstrates how staff members sometimes do not respond to service users' demonstrations of readiness because of safety reasons. It is not always because the staff member has not yet prepared a spoonful of food or is not attending to the service user when they demonstrate their readiness.

11.7.3 Overview of Section 11.7

11.7.3.1 Summary of behaviours used. In the extracts in this section service users demonstrated their readiness by looking towards the food, vocalising, leaning towards the food, opening their mouths, reaching for the spoon, banging on the table and/or salivating. It is not possible to know for sure whether these behaviours were designed to elicit a response from the staff member but they all appear to demonstrate the service user's readiness to continue with the mouthful sequence.

11.7.3.2 Service users' first pair parts. I believe the most important point that can be taken from this section is the fact that service users can initiate mouthful sequences. By opening their mouth or reaching for the spoon, when the staff members are unready, service users can demonstrate readiness. Such interactions look like purposeful initiations. However, it is not possible to say that this is definitely the case since there may be a number of explanations for their behaviour. However, even if, in some instances, these behaviours were not completed for a target recipient, they still appear to

demonstrate readiness. This means they can be treated as a legitimate initiation of the mouthful sequence.

11.8 Eye-gaze in mealtime interactions

As noted earlier, every transcript is necessarily selective. It is impossible to provide detailed information about every aspect of an interaction in a single transcript. Whilst in the transcripts provided I have rather crudely noted gaze, this could have been done in significantly more detail (as by Kendall, 1967; Goodwin, 1980; Rossano 2012). There could have been a whole chapter on gaze and the references to it in this chapter are relatively few in an effort to strike a balance. In an attempt to avoid data overload but still pay due attention to this important behaviour I have noted it when it appeared important for the unfolding of the interaction in the transcripts. I have also paid some particular, focused, albeit brief, attention to it in this section.

As Rossano (2012) acknowledges, gaze has several functions. Some of these are interactional. In typical interactions gaze orientation is important to demonstrate when it is a speaker's turn to contribute (Sacks, Schegloff, 1974). It is also used by recipients to demonstrate that they are listening or attending (Kendon, 1967; Bevelas, Coates & Johnson, 2002). Kendon (1967) and Goodwin (1980) have both highlighted the importance of gaze for monitoring behaviours in interaction.

Gaze is particularly important in interactions involving people with severe intellectual disabilities. First, because of their limited expressive communicative repertoire, gaze is a resource which may convey meaning that is difficult to discern otherwise. For example, in Extract 16, Jake looks towards his food. He is probably demonstrating that he is ready for the upcoming mouthful. Second, just as gaze in important in typical interactions to signal when it is a participant's turn in conversation, it may be particularly important for those with limited receptive communication, or understanding. Looking towards a person with severe intellectual disabilities may signal that is their turn within an interaction. For example, in Extract 17, Tom looks towards the spoon and food immediately prior to Jenny taking the spoon which Tom is holding. Finally, monitoring is vital for a number of reasons.

Monitoring may be important during mealtime interactions involving people with severe intellectual disabilities because of the increased medical risks, such as risk of choking or experiencing swallowing difficulties. Such incidents may occur suddenly with

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little warning. Whilst gaze is generally an important resource for people with severe intellectual disabilities, it is of particular importance in mealtime interactions for care staff to monitor the service users. In addition to medical risks, some behaviours of people with severe intellectual disabilities may be particularly subtle. Examples include slight changes of facial expression or body posture which may be meaningful in an interaction but require the staff member to closely monitor the service user's behaviours to be able to respond to them.

Picture 6-8 below capture some staff members monitoring behaviours during mouthful sequences. They alter their own position to monitor effectively throughout.
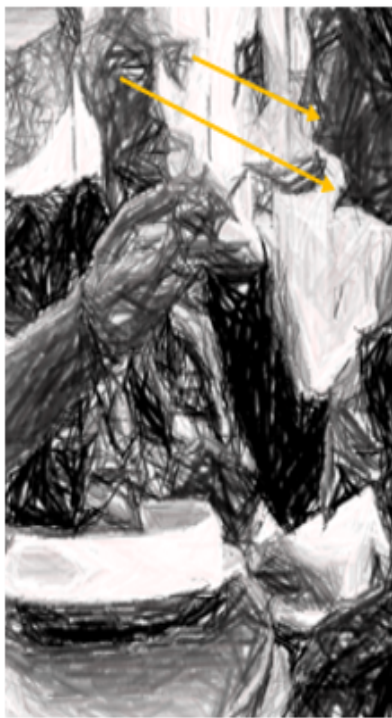
(a)   (b)

Figure 54a – Picture 6, Thomas monitors Jenny using eye gaze while they move food towards her mouth.

Figure 54b – Picture 7, Thomas changes his body and head position to continue monitoring Jenny as they raise their hands so Jenny to eat.

Figure 55 – Picture 8, Emma leans downward to look up at Jenny's mouth before supporting Jenny with the next spoonful, which Jenny is reaching for.

When service user behaviours go unnoticed, quite often this appears to be due to staff members directing their gaze elsewhere. Sometimes this was because the carer's attention was diverted to tasks unrelated to the service user's mealtimes. At others it was due to performing necessary mealtime tasks such as collecting cutlery, plate guards, rolling tissue or chopping food.

11.9 Staff and Service User Attuning to One Another

Griffiths and Smith (2016) suggest that successful interactions require people to be highly attuned to the other. They discuss what attunement between care staff and people with severe -profound intellectual disabilities entails and offer examples from their own dataset.   Stern defined attunement as "the performance of behaviours that express the quality of feeling of a shared affect state without imitating the exact behavioural expression of the inner state" (Stern, 1985, p.142) This was extended by Forster (2011) who defined it as matching vocal, facial, postural and gestural behaviours. Whilst considerably more complex than there is the scope to discuss here, much of attunement relates to people synchronising their actions with others. In particular, Griffiths and Smith measure the extent of attunement between people on two dimensions – empathy and co-operation. They define empathy as relating to understanding the other's wishes whereas co-operation relates to working together to

achieve the same goal. Having 'attuned' mealtime partners is important and work such as that of Griffiths and Smith (2016) is promising for the development of future frameworks which may be valuable for support workers.

An example of a harmonious interaction, offered by Griffiths and Smith (2016), is where Mary supports Tony during a mealtime. They note that "He opens his mouth as the spoon arrives, she inserts the spoon and he takes the food. Tony's anticipation of the spoon and his response to that anticipation (opening his mouth) allows the easy insertion of food, and a calm, rhythmic coordination of actions" (p.131). This chapter gives detailed accounts of mouthful sequences when this does, and does not occur. There is not scope to provide full details of entire mealtimes I observed. However many of the examples which appeared to me to be synchronised, and where empathy for the other person and full co-operation between the parties seemed to be achieved through their actions often remained so throughout the interaction. In this chapter, Emma noticing and understanding Jenny's salivating in extract 19 would be considered as empathy, and people with severe intellectual disabilities opening their mouths when presented with spoons demonstrates co-operation.   Likewise, if empathy and co-operation seemed not to be achieved, this too was likely to persist throughout the interaction.

It is difficult to envision how empathy and co-operation are fostered without good relationships between staff member and service user. The subject of Relationships is discussed in chapter 9. The emotional aspects of sharing food with others and how mealtimes can aid relationships particularly for adults with severe intellectual disabilities is outlined by Schwier and Stewart (2005). Their heart-warming, life-affirming book, provides several accounts of interactions with people with disabilities (very often intellectual disabilities). It emphasises the enjoyable elements of mealtimes. One aspect of enjoying mealtimes they discuss involves indulging in high-calorie food on special occasions (such as eating birthday cakes at parties) and being able to enjoy special meals, restaurants and picnics. They also encourage the involvement of people with intellectual disabilities in the cooking process. Yet, Schwier and Stewart (2005) do not always fully acknowledge many of the potential risks associated with mealtimes involving people with severe intellectual disabilities. These include nutritional and medical risks.

11.10 Relating mealtime behaviours to decision making capabilities

Many examples in this chapter demonstrate that people with severe intellectual disabilities have the ability to make some decisions. Examples include not wanting to eat at certain times, such as when they are still eating their previous mouthfuls, wanting to engage in other activities at mealtimes including speaking, banging objects and drinking as well as seemingly wanting the next mouthful of food when the staff member is not ready to provide it.

Whilst it can be difficult to assess the extent to which the behaviours of people with severe intellectual disabilities are intentional, the choices they are expressing in the extracts presented in this chapter at least appear to demonstrate decision making abilities. Currently, the DSM-5 states that people with severe intellectual disabilities "cannot make responsible decisions regarding well-being of self or others" (p.36). Yet, deciding not to open your mouth for another mouthful of food while you are still eating looks like a responsible decision. This happened regularly in my sub-corpus. It is not easy to define what is, and is not, a "responsible decision". The term requires clarification. I suggest that it depends on the context of the decision in hand, and the risks associated with it. Many of the extracts presented offer examples of interactions that suggest that people with severe intellectual disabilities can make decisions and that at times these decisions are not treated as legitimate.

Being more responsive to the decisions that people with severe intellectual disabilities appear to make during mealtimes is likely to have positive psychosocial benefits, such as increased feelings of autonomy, as well as potential medical benefits, such as decreased swallowing difficulties which can be a result of the mealtime being paced too fast.

There is only one isolated example in the sub-corpus where Jenny, one of the participants with severe intellectual disabilities, actively demonstrated she was ready for another mouthful being the "first player" in the mouthful sequence, despite the fact she still had food in her mouth (see Extract 33). This decision does not appear to be responsible. By contrast staff often encouraged service users to eat when they still had food in their mouth. Also, in the isolated episode, Jenny had been exhibiting behaviours which were considered by both staff and myself to demonstrate she was particularly hungry (see subsections 11.6.1.3 and 11.6.2) and was left for longer than usual without

her food whilst being able to observe another service user eating.   Whilst in this instance, Jenny appears to be attempting to eat too quickly, this may not be an issue that is specific to people with severe intellectual disabilities. Several newspaper articles and internet blogs discuss the same problem amongst the typically developed population (e.g. Dillner, 2017). This is not to disregard the increased risk that such behaviours cause Jenny. The importance of Emma's monitoring of Jenny is highlighted as she encourages Jenny to wait until she has swallowed, reducing that risk. To suggest that people with severe intellectual disabilities can make decisions that are always responsible may be incorrect. However, not to acknowledge the capabilities of service users and their ability to express them is also limiting. In this sub-corpus there were several more examples of service users seemingly making responsible decisions.

11.11 Discussion

11.11.1 Dysphagia management. The examples presented in this chapter suggest that communication and interactional co-ordination is an important aspect of dysphagia management. For example, if staff are alert to the ways by which service users may demonstrate that they are not ready for a new spoonful of food, (perhaps because they are still eating the food from the previous mouthful), then the pacing of the mealtime could be adjusted, making it safer for the person with severe intellectual disabilities to eat. It has been suggested that if communication relating to eating and drinking is effective during mealtimes then risks relating to swallowing are reduced (e.g. Harding & Halai, 2009; Mathisen, 2001). However, few real life detailed examples have been provided.

Chadwick et al (2003) discovered that advice relating to support, prompting and socialising was the least adhered to out of all dysphagia management guidelines. Fifteen years later and the examples presented in this chapter suggest that this is still a problem. Some of the behaviours exhibited by staff members were contrary to what was set out in the service user's mealtime guidelines.   This needs to be addressed, and may relate to insufficient training and paid time set aside for staff to review guidelines as needed, and lack of communication in the service. Other practical issues may include where the guidance is kept. For example, keeping files in the offices of senior management as was the case in one centre, may make it more difficult for staff to quickly refresh their memory on the best way to support a particular person.

It is hoped that this chapter outlines how real-life personal examples could be used to provide objective evidence for appropriate (and inappropriate) interaction support which could be included in an individual's person-centred planning. Sequences that apply more broadly across mealtime interactions involving different people with severe intellectual disabilities could also be established. A list of suggested guidelines are provided at the end of this chapter.

11.11.2 Limited choices. Robinson et al., (2016) suggested that some psychosocial risks that people with intellectual disabilities may experience relating to mealtimes include a reduction in the choice of food or drink. The extracts presented in this chapter demonstrate that further risks can include a lack of choice relating to when and how quickly they eat and drink. However, in some cases service users appeared to control the pace at which they ate. Service users were also not given any choice relating to who they spent their mealtimes with. These considerations, alongside those relating to swallowing, breathing and general nutrition should be considered in risk assessments.

11.11.3 Social activity. There were some examples of social activity occurring at mealtimes. Not all interaction in the video related to the environment or the eating and drinking process. For example, Jenny was regularly playful at mealtimes, particularly in Luke's company. However, the footage in this sub-corpus followed trends of previous research (e.g. Bailey et al., 1983; Ferm et al., 2005), and the overwhelming amount of time was spent ensuring the people with severe intellectual disabilities ate and drank, with many interactions seeming not to focus on creating a two-way, social, mealtime interaction similar to those described by Schwier and Stewart (2005).

11.11.4 Intentionality. An important point that occurred after studying the mealtime interaction sub-corpus was that even if behaviours are unintentional, they are still available for the staff members to respond to. One of the key aspects of conversation analysis is turn design (see chapter 6), and the idea that interactional turns are designed for the recipient of them. However, many of the behaviours exhibited by people with severe intellectual disabilities are not intentional. Examples found in the sub-corpus include coughing, breathing difficulty and salivating. It is clear that staff respond to these behaviours. To some extent it does not matter that these behaviours are not produced for the purpose of communicating with another, as they can still provide the staff members with valuable information which can shape the interaction.

11.11.5 Monitoring the actions of the person with severe intellectual disabilities.
After examining the videos in the sub-corpus, it became apparent that monitoring was an important element to successful mouthful sequences. This is demonstrated by staff clearly monitoring service users' mouthfuls when mouthfuls were successful, as described in section 11.8, and staff missing service user cues, as can be seen for example in Extract 31. It is important that staff understand how subtle some initiations by service users may be and the need to actively look for behavioural cues.

Times when this was difficult included staff members being distracted from the service users' mealtime and the competing demands related to the task in hand. Ideally, the meals would be fully prepared before being brought to the service user. This would ensure that the food is appropriately modified and that necessary equipment, such as plate guards are available. Additional preparation which could allow the eye gaze of staff not to be distracted away from the person with severe intellectual disabilities includes making sure that tissue is available and pre-rolled and that the food is already at an appropriate temperature.

11.11.6 Acknowledgement and promotion of people with severe intellectual disabilities as active participants in mealtime interactions. Even if staff members appropriately monitor the behaviour of the person with severe intellectual disabilities, if they do not fully acknowledge the person's role as an active participant in mealtime interactions and fail to treat their behaviours as legitimate, then this is still problematic. If staff notice that a person with severe intellectual disabilities is following a different course of action, or simply unready to eat or drink, but do not respond to it, the interaction is still likely to experience trouble. Even if the person with severe intellectual disabilities complies with the eating and drinking activity, to ignore or disregard their behaviours is to undermine an everyday decision they are likely to be able to make and express.

 I believe it is important to promote people with severe intellectual disabilities to be as active as possible in all interactions including mealtimes. One way to do this is to ensure that they are given the opportunity to be the "first player" in meal-time sequences. Examples of such sequences are presented in section 11.7. Furthermore, even when a person with severe intellectual disabilities is unready, if the carer waits and does not withdraw a demonstration of readiness, then the service user is given the

control to choose when they are ready. If this were to occur, they would not need to rely upon a re-demonstration of readiness from the person supporting them.

11.11.7 Patience. Directly related to not withdrawing demonstrations of readiness when a service user appears unready, being appropriately patient when supporting people with severe intellectual disabilities is vital. Rushing through the mealtimes can mean that the pace is too fast and cause health risks. Similarly, not responding to initiations of social activity by the person with severe intellectual disabilities brings the psychosocial risks of disempowerment and social isolation. A further reason to ensure interactions are not too fast is that people with severe intellectual disabilities may also take longer to understand the behaviours of others and to plan and execute a response (Porter et al, 2001).

11.11.8 Transferring and sharing positive strategies. Whilst there were still examples of service users' readiness not being responded to, mealtimes appeared to be an activity where service users were, in general, more involved than they were during other activities.   I believe this is partly due to the nature of the activity and the fact that it must be co-achieved. Behavioural sequences or routines that are established may also allow for further communication and interaction to take place (as with Goode, 1994).   If such behavioural routines were similarly established during other activities, such as waiting for a service user to open their hand, or reach for a paintbrush, before proceeding with a painting activity, such interactions may become more equal and the service user more involved. It would be important to respond consistently to such behaviours and may take time to establish behavioural patterns. However, once behavioural sequences were learnt that depended upon the involvement of the person with severe intellectual disabilities, space to resist such activities, or for further communication may exist. This warrants further research.

I suggest that positive strategies from mealtimes may be transferrable across activities and between staff members. Some staff members consistently appear to have well synchronised interactions where both parties appear to be happy (or at very least not unhappy), whilst responding to the other's actions seemingly attuned to one another. It may be that staff members are able to learn from each another. However, we cannot assume just because the staff members are skilled communicators that they will be able

to identify and articulate their skills/strategies (as exemplified by Healy & Noonan Walsh's research, 2007).

11.11.9 Tips for care staff. Arising from my observations, I suggest the following practical tips for care staff supporting people with severe intellectual disabilities at mealtimes. It is not an exhaustive list.

Before the Mealtime

1. If possible, service users should be paired with support staff they know well and like.

2. If communication passports and eating and drinking guidelines specific to the service user are available, be familiar with them.

3. Be aware of the service user's likes and dislikes including food and drink, where and how to sit and who supports them. Try to accommodate them.

4. Ensure you have all the necessary equipment and food (modified if necessary) before commencing the mealtime interaction. Otherwise, the mealtime can be interrupted and the service user made to wait even when ready.

During Mealtimes

5. Observe the service user throughout, monitoring behaviour, looking for verbal and non-verbal cues, initiations and responses.

6. Acknowledge and respond appropriately to the service user's behaviour, respecting the legitimacy of their actions.

7. If possible establish a mouthful sequence where the service user makes the first move so that they have more control in the interaction.

8. If not possible, demonstrate you are ready to support the service user to take the next mouthful in a consistent way that is meaningful for the particular user. For example, for one person it may be appropriate to fill the spoon and leave it in a certain position on the plate. For another, who may be less mobile or have limited vision, food may need to be presented near to their face.

9. Do not hurry. Wait for service user responses.

10. Do not demonstrate readiness for a new mouthful sequence if the person with severe intellectual disabilities still has food in their mouth. Monitor the person closely to check this.

11. If a service user is not ready for another mouthful it may be best to continue to demonstrate your readiness.

12. Do not repeatedly try to elicit a demonstration of readiness from the person with severe intellectual disabilities without providing them with appropriate time and space to respond. If a person is turning their face away from a spoonful of food, do not follow their mouth with the spoon.

13. Physical prompts, such as touching a person's arm or slightly wiggling the spoon, and verbal prompts, such as use of names, may help elicit a demonstration of readiness.   These may be most successful when used together. However, these should be used sparingly.

14. Appreciate the signals which may demonstrate readiness (such as opening mouth , reaching for food or drink, looking towards staff member or food and stopping other activities) and those that may demonstrate unreadiness (such as by looking or turning away from food and staff member, leaning away, pulling grimacing facial expressions or involuntary actions such as coughing or having difficulty swallowing or breathing). A lack of behaviours which demonstrate readiness may also signal that the service user is unready.

15. Respond to and encourage behaviours that are social at mealtimes. Do not make mealtimes simply about "getting the task done".

12. Concluding Comments, Implications and Applications

In this thesis each analytical chapter has a discussion section where conclusions are drawn, and the implications and applications of the findings are considered. This chapter aims to provide an overview of findings that relate to all the themes before briefly highlighting the major contributions from each chapter.

12.1 Overview of General Findings

12.1.1. People with severe intellectual disabilities making decisions. Perhaps the biggest take-home point from this research is that, at times, the participants with severe intellectual disabilities appear to be able to make decisions relating to their well-being. Examples include service users deciding which activities they complete and which they do not, which members of staff they want to be with, when they will eat, at what pace and how much. It is important to acknowledge that people with severe intellectual disabilities may demonstrate their wants, needs and preferences in subtle ways to enable them to be able to make choices in their lives. The more they are viewed as agentic, the more sensitive people may become to their communication, and the more opportunities may be provided to them. It is also accepted that having some control over one's own life and being able to make choices relating to it (such as relationships and mealtimes), improves quality of life (Maes, Lambrechts, Hostyn & Petry, 2007).

As discussed throughout this thesis, this appears to be in contrast to a specifier of the impairments experienced by people with severe intellectual disabilities set out in the DSM-5, which states "The individual cannot make responsible decisions regarding well-being of self or others" (p.36, APA, 2013).   Below I set out some possible reasons why the potential decisionmaking abilities of people with severe intellectual disabilities may have been overlooked. Often when decisions relating to people with intellectual disabilities are discussed, there is a focus on big choices such as the management of money, medication or where to live (e.g. DoH 2001, 2009). I do not suggest that people with severe intellectual disabilities should be assumed either capable or incapable of making, or being involved in making, these 'big' decisions. However, such decisions are likely to have a heavier cognitive load and involve advanced planning and assessment skills that may not be required in smaller everyday decisions, such as the timing of opening your

mouth during mealtimes or which member of care staff you prefer to be with. Seeking the company of people who make you happy, or not opening your mouth for a new mouthful of food before you have finished the last, still appear to be responsible decisions which relate to a person's own well-being. This focus differs from the emphasis in Government documents which give prominence to the "big" decisions without a sufficient focus on the smaller (DoH, 2001, 2009).

That said, people with severe intellectual disabilities may need additional help to make more complex decisions as they may not be able to assess all the potential associated benefits and risks. Whether the benefits and risks of any situation are significantly additional to those that could be understood by the person with severe intellectual disabilities is not necessarily always easy to assess. However, the potential risks and benefits of a person leaving an activity session or seeking out the company of a particular person are likely to be considerably less than resisting the application of medicinal cream, for example. Ideally, the decisions and choices of people with severe intellectual disabilities should be acknowledged and enacted when possible and safe to do so.   This may not always be an easy call to make. In practice there may be different views about what is and is not safe. Where a person resists the application of a medical cream, their choice should at least be acknowledged, even when it cannot be enacted. Some situations may also need to take account of the institutional context. For example, if a person with severe intellectual disabilities wants to go to the park but there are insufficient parks to achieve this, it simply may not be possible to achieve. Striking a perfect balance between empowering individuals, appropriate safeguarding and the practical limitations of an institutional context is difficult but should be something for which we continuously strive.

As argued elsewhere (Nicholson, 2017), I suggest that the APA should revise how the skills of people with severe intellectual disabilities are defined.   It is vital to ensure that their   capabilities are not underestimated. A discussion about the decision making capabilities of people with severe intellectual disabilities would hopefully engage academics and front-line staff alike and begin to challenge potentially limiting perceptions of people with severe intellectual disabilities.

12.1.2 Suitability of Conversation Analysis. Whilst there is a growing body of conversation analysis research involving people with intellectual disabilities, the research

which focuses on interactions involving people with severe or profound intellectual disabilities is considerably more limited (although see Antaki, 2017, for a noticeable exception). It is hoped that this thesis has demonstrated how the structure and sequence of interactions involving people with severe intellectual disabilities can be meaningfully analysed using the main principles of conversation analysis. As discussed in chapter 6 (Conversation Analysis and Ethnomethodology), interactions which involve people with severe intellectual disabilities will not always conform to the assumptions made by conversation analysts largely due to the varying abilities of participants with intellectual disabilities. However, the approach provides a framework to be able to note what is actually occurring in interactions, which behaviours form interactional turns and the sequence which those turns follow. In short, CA allows for interactions to be clearly detailed and analysed. Examining the interactions presented here can also add to the general understanding of interactions. For example, the non-verbal extracts in this thesis offer support for the claim that adjacency pairs can be entirely non-verbal, something that Schegloff originally challenged (1992). Not only can adjacency pairs be observed in non-verbal interactions in typically developed populations (as Clark, 2006) and young children (e.g. Learner & Zimmerman, 2003) but such sequences can also be observed in interactions involving people with severe intellectual disabilities. This both offers insight into how interactions involving people with severe intellectual disabilities are structured and supports the idea that these interactions are suitable for examination using conversation analysis.

One further reason why conversation analysis appears to be a useful approach to examine interactions involving people with severe intellectual disabilities is because it allows examples to be provided and presented. Much of the literature to date involving people with severe intellectual disabilities has been polarised. Many researchers have examined and counted certain behaviours without providing the sequential details of when these behaviours occurred (e.g. McConkey et al, 1999). Others, within the "grey literature", provide rich detailed examples of interactions similar to those detailed from my ethnographic notes, but leave themselves open to criticism that their approach is anecdotal and lacks empirical value (e.g. Nind & Hewett, 2001; Caldwell, 2005). Conversation analysis bridges the gap. It allows for behaviours to be presented in sequential order, for the video data to be watched and re-watched to ensure subtle

behaviours are not missed and can be presented on the page in a way which allows the reader to challenge the analyst's interpretation. Without sacrificing the rich details of an interaction, an empirical, systematic approach can be applied.

In the course of this research, the importance of looking at the micro aspects of interaction was evident, but it became apparent that being aware of the overall shape, or trajectory, of an interaction can be equally important. For example, in chapter 10, Resistance, some examples would not capture the full extent of resistance if they were not considered holistically as a whole interaction. Robinson (2012) states that looking at the 'sequence of sequences' and how interactions are structured as a whole is of interest to conversation analysts but acknowledges that related research is relatively limited. Many current researchers are addressing this issue (e.g. Fitzgerald, 2017). However, there is still a paucity of relevant research.

12.1.3. Using other methods alongside Conversation Analysis. Traditionally the idea of using conversation analysis alongside other methods has been questioned by leading academics in the field (e.g. Schegloff, 1993). However, this debate has been rejuvenated recently. For example, as Kendrick (2017) outlines, researchers are using experiments and laboratory resources alongside conversation analysis, reaping the benefits of such an approach. Although the research presented in this thesis does not adopt this approach, I hope my research demonstrates the benefits of using various methods together.   Particularly when taking an explorative approach to research and not testing hypotheses, completing ethnographic notes and interviews can be particularly useful, allowing for a broader understanding of the institution and the people within it to accompany the analysis of actual recorded interactions. In chapter 9, Relationships, three different approaches were used to address the same research question: "Is there evidence of close relationships between care staff and service users?". The use of coding and counting of behaviours (in this thesis, partial interval recording), allowed for behaviour use to be quantified, even if much of the data provided by a fine grain micro analysis is lost. Quantification was useful in this research because it allowed comparison between different interactional partners. Through interviews it was possible to explore local understandings of relationships between care staff and service users. This may not have been possible otherwise. The interview data complemented the conversation

analysis findings. The three approaches provided support for each other and is a technique I would recommend.

12.1.4 Multiple factors influence interactions involving people with severe intellectual disabilities. As I began this exploratory research, one of the over-arching questions was "What influences interaction?" closely linked to "What do "good" interactions look like?" Whilst I never expected to find perfect answers to these questions, they guided my research. Some of the potential answers to the question "What influences interaction?" formed the basis of each of the four analytical chapters of this thesis. First, the perceived vulnerability of people with severe intellectual disabilities affects the interactions they are included in, and how they are treated within those interactions. Second, the relationships between the people involved in the interaction can also change how the interaction may look. Third, the ability of the person with severe intellectual disabilities to resist activities, and the responses which their resistance elicits, also appear to shape interactions. Finally, the activities that are being completed within the interaction also influence it. An example of a special type of interaction is during supported mealtimes. That is one of the reasons why mealtimes became the subject of my fourth analytical chapter. These are only a few of the potential factors which have an influence on interactions. It is important that researchers and people supporting people with severe intellectual disabilities alike appreciate the numerous factors that can alter interactions and how they may do so.

12.1.5 Intentionality. When examining interactions involving people with severe intellectual disabilities it can be difficult to establish which behaviours are intentional and designed for a target recipient and which are automatic and are not designed for others. In many ways this is one of the most difficult challenges to overcome when working with video recording of such interactions. Other researchers have focused upon establishing potential identifiers of intentional behaviours (e.g. Iacono, Carter & Hook, 1998). However, as demonstrated in this thesis, depending on the research question, it may not be necessary to establish which behaviours are intentional. Even behaviours that may not be designed for a target recipient are available for the recipient to access and respond to. For example, if a person with severe intellectual disabilities is demonstrating emotions by crying or smiling, it does not matter whether these behaviours were designed for other people. The behaviours still convey potentially useful information.

Conversation analysis allows for the behaviours of an interaction to be recorded and analysed sequentially providing an opportunity to examine social action without assuming knowledge of the participant's inner thoughts. In this way, the approach accommodates data where it is difficult to ascertain intentionality.

12.2 Major Contributions from Each Chapter

12.2.1 Vulnerability. The perceived vulnerability of people with severe intellectual disabilities can affect interactions. For example, the perceived vulnerability of people with severe intellectual disabilities as judged by ethics board members, care staff and family can all influence which activities people with severe intellectual disabilities are involved in and how they are treated during these interactions.

There are several genuine risks associated with severe intellectual disabilities and some perceived vulnerability is real. However, it is important that we consider all risks and impacts – not only the immediate ones. For example, it is suggested that sheltering adolescents and young adults with intellectual disabilities from risks related to relationships and sex makes them more likely to be sexually abused as adults (Franklin et al., 2015). It may be that always keeping a person indoors when it is cold reduces the risk of infection but also increases the risk of being excluded from the community. Excluding a person from experiences because there are not enough staff trained to support particular medical needs may mean that immediate medical risks are reduced but that long term social risks of isolation and psychological risks of experiencing negative emotions are increased.

Generally, risk is assessed across two dimensions, severity and likelihood (Alberg, Hatfield & Huxley, 1996). I suggest that potential impact over time should also be considered. An adapted risk assessment form is presented in chapter 8, Vulnerability, which considers a third dimension.

12.2.2. Relationships. It is demonstrated by the case study in chapter 9 that close interpersonal relationships can exist between care staff and service users. Evidence of such relationships is apparent when examining interactions using a variety of methods. Jenny demonstrates her relationship with Luke non-verbally, with her positive behaviours increasing with Luke's increased availability. Luke orients to their close interpersonal relationships in his talk, when speaking to Jenny and other members of staff. Yet the

acknowledgement of such interpersonal relationships within formal guidance or within the related literature is limited. This is despite the fact that close relationships are crucial to wellbeing (Knox & Hickson, 2001). People with severe intellectual disabilities should have the opportunity to develop and sustain those relationships. It is important that we acknowledge these relationships exist, that the potential benefits and risks associated with such relationships are assessed, so that guidelines related to them can be formed. Unfortunately, this was outside the scope of this thesis but is an area ripe for further research. Decisions about support and leisure times should also enable people with severe intellectual disabilities to spend time with people they are close to.

12.2.3 Resistance. In this chapter, it is demonstrated that resistance to an activity, like an interpersonal relationship with a person, can be demonstrated in interactions non-verbally. It is established that resistance can be passive or active. Pretending or choosing to go to sleep has been reported as a strategy used by people with severe intellectual disabilities to resist activities (Porter et al., 2001). Leudar and Fraser (1985) also outlined examples of people with intellectual disabilities purposefully being uncooperative as a withdrawal method. To my knowledge, the research presented is the first to provide clear examples of participants with severe intellectual disabilities seemingly deliberately feigning sleep as a withdrawal strategy.

I also note the distinction between resisting a whole activity and resisting one element of an interaction. However, distinguishing exactly what a person with severe intellectual disabilities is resisting is not always easy. It is important that we start to address ways to ensure that people with severe intellectual disabilities are able to resist activities, or elements of them, easily and that staff respond appropriately to such behaviours. The role that physical mobility has in being able to resist activities is noted and it is suggested that by promoting physical independence people may find it easier to resist activities and express choices and decisions about how they spend their time. Staff members are likely to benefit from training relating to resistance and decision making.

12.2.4 Mealtime interactions The final analytical chapter of my thesis demonstrates that mealtime interactions involving people with severe intellectual disabilities are sequentially organised. Dispreferred and preferred responses are identified and shown to share features which can be found in interactions involving typically developed people. My findings also demonstrate that people with severe

intellectual disabilities can initiate mouthful sequences, and examples of how this is achieved are provided. Various staff responses are also noted and the importance of eye gaze to monitor service users is highlighted. Current eating and drinking guidelines do not tend to focus much on the interactional elements of mealtime interactions instead offering advice relating to issues such as food modification, dietary requirements and specialist equipment (Chadwick et al, 2003). This chapter demonstrates that this means a valuable resource is currently being underutilised. It is important that guidance given to speech and language therapists and care staff which pertains to mealtimes includes both the interactional cues relating to completing the task and social information that may make the meal time more enjoyable.

12.3. Final words

To include all that I noticed, learnt, discovered, heard, saw and felt whilst completing this research project would be impossible. The different directions this research has taken me in are evident by the variation in topics covered and approaches used in each analytical chapter. In this final concluding chapter, it is hoped that the scope of how very much we can learn simply by examining everyday interactions involving people with severe intellectual disabilities is illustrated. I suggest that the need for more research using similar approaches within this field is urgent.

References

Alberg, C., Hatfield, B., & Huxley, P. (1996). Learning materials on mental health: Risk assessment. *Manchester: University of Manchester/Department of Health*.

Albert, S. (2014a) *Managing video data.* 2nd EMCA Doctoral Network Meeting – Skills Sessions. London.

Albert, S. (2014b). *ICCA 2014 and the Future(ology) of CA .* Available: saulalbert.net/blog/icca-2014-and-the-futureology-of-ca/. Last accessed 10th November 2018.

Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and developmental disabilities*, *51*(5), 360-375.

Aman, M. G., & Handen, B. (2006). Reactions to "Ethical challenges and complexities of including people with intellectual disability as participants in research" by Dr Teresa Iacono. *Journal of Intellectual and Developmental Disability*, *31*(3), 180-182.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington : American Psychiatric Publishing.

American Psychological Association. (2017). *Ethical principles of psychologists and code of conduct* (2002, Amended June 1, 2010 and January 1, 2017). Available: http://www.apa.org/ethics/code/index.aspx. Accessed 20th November 2018.

Anderson, C. (2006). Early communication strategies: using video analysis to support teachers working with preverbal pupils. *British Journal of Special Education*, *33*(3), 114-120.

Anderson, C. (2008). Supporting communication with non-verbal children in the classroom. *The SLD Experience*, *50*(1), 17-21.

Anderson, G. and Kazantzis, N., 2008. Social problem-solving skills training for adults with mild intellectual disability: A multiple case study. *Behaviour Change*, *25*(2), pp.97-108.

Antaki, C., & Wilkinson, R. (2014) Conversation Analysis and the Study of Atypical Populations In J. Sidnell and T. Stivers (Eds.), *The Handbook of Conversation Analysis.* pp. 511 – 532. Sussex: Wiley-Blackwell.

Antaki, C., Crompton, R. J., Walton, C., & Finlay, W. M. L. (2017). How adults with a profound intellectual disability engage others in interaction. *Sociology of health & illness*, *39*(4), 581-598.

Antaki, C., Finlay W.M.L., Walton,C., and Pate, L. (2008) Offering choices to people with intellectual disabilities; an interactional study *Journal of Intellectual Disability Research 2008 Dec pp 1165-75*

Antaki, C., Finlay, W. M. L., & Walton, C. (2007). The staff are your friends: Intellectually disabled identities in official discourse and interactional practice. *British Journal of Social Psychology*, *46*(1), 1-18.

Antaki, C., Finlay, W. M. L., & Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday practice. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(4), 260-266.

Antaki, C., Finlay, W. M. L., Sheridan, E., Jingree, T., & Walton, C. (2006). Producing decisions in service-user groups for people with an intellectual disability: Two contrasting facilitator styles. *Mental Retardation*, *44*(5), 322-343.

Antaki, C., Finlay, W. M. L., Walton, C., & Sempik, J. (2016). Communicative practices in staff support of adults with intellectual disabilities. In *The Palgrave Handbook of Adult Mental Health* (pp. 613-632). Palgrave Macmillan, London.

Antaki, C., Walton, C. and Finlay, W.M.L., (2007) How proposing an activity to a person with an intellectual disability can imply a limited identity. *Discourse & Society, 18 (4), pp. 393-410*

Antaki, C., Young, N., & Finlay, M. (2002). Shaping clients' answers: departures from neutrality in care-staff interviews with people with a learning disability. *Disability & Society*, *17*(4), 435-455.

Antonak, R., & Livneh, H. (2000). Measurement of attitudes towards persons with disabilities. *Disability and rehabilitation*, *22*(5), 211-224.

Atkinson, J. M., Heritage, J., & Oatley, K. (Eds.). (1984). *Structures of social action*. Cambridge University Press, Cambridge.

Bailey Jr, D. B., Harms, T., & Clifford, R. M. (1983). Social and educational aspects of mealtimes for handicapped and nonhandicapped preschoolers. *Topics in Early Childhood Special Education*, *3*(2), 19-32.

Ball, S. L., Panter, S. G., Redley, M., Proctor, C. A., Byrne, K., Clare, I. C. H., & Holland, A. J. (2012). The extent and nature of need for mealtime support among adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *56*(4), 382-401.

Barber, M. (2008). Using Intensive Interaction to add to the palette of interactive possibilities in teacher–pupil communication. *European Journal of Special Needs Education*, *23*(4), 393-402.

Bavelas, J. B., Coates, L., & Johnson, T. (2002). Listener responses as a collaborative process: The role of gaze. *Journal of Communication*, *52*(3), 566-580.

Beadle-Brown, Whelton, Richardson, Beecham, Baumker & Bradshaw (2016) Quality of Life and Quality of Support for People with Severe Intellectual Disability and Complex Needs. *Journal of applied research in intellectual disabilities 2016 Sep 29:5 pp409-421*

Beake, S., Maxim, J., & Wilkinson, R., (2007) Using conversation analysis to assess and treat people with aphasia *Seminars in Speech and Language* 28(2): pp136-47

Beauchamp, T. L., & Childress, J. F. (1989). The principles of justice. *Principles of Biomedical Ethics*, *3*, 256-306.

Becker, H., Roberts, G., Morrison, J., & Silver, J. (2004). Recruiting people with disabilities as research participants: Challenges and strategies to address them. *Mental Retardation*, *42*(6), 471-475.

Bellamy, G., Croot, L., Bush, A., Berry, H., & Smith, A. (2010). A study to define: profound and multiple learning disabilities (PMLD). *Journal of Intellectual Disabilities*, *14*(3), 221-235.

Belva, B. C., Matson, J. L., Sipes, M., & Bamburg, J. W. (2012). An examination of specific communication deficits in adults with profound intellectual disabilities. *Research in developmental disabilities*, *33*(2), 525-529.

British Institute of Learning Difficulties (2016). What is active support?? Birmingham: BILD. Available: http://www.bild.org.uk/capbs/active-support/. Last accessed: 20th November 2018.

Bloch, S., & Antaki, C. (2018). The Pivot Point between Problem Presentation and Advice in a Health Helpline Service. *Applied Linguistics*. Available: https://academic.oup.com/applij/advance-article-abstract/doi/10.1093/applin/amy014/4953515?redirectedFrom=fulltext

Bowley, C., & Kerr, M. (2000). Epilepsy and intellectual disability. *Journal of Intellectual Disability Research*, *44*(5), 529-543.

Bradshaw, J. (2001). Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of Intellectual Disability Research*, *45*(3), 233-243.

Bradshaw, J. (2015). *Communication and Challenging Behaviour.* Available: https://www.challengingbehaviour.org.uk/learning-disability-files/04---Communication-Information-sheet-web.pdf. Last accessed 20th November 2018.

British Psychological Society. (2009). *Code of Ethics and Conduct.* Available: https://www.bps.org.uk/files/code-ethics-and-conduct-2009pdf. Last accessed 20th November 2018.

Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 11-18.

Bruce, S. M., Cascella, P. W., Ivy, S., & Trief, E. (2009). The development of a universal tangible symbol system. *Journal of Visual Impairment & Blindness*, *103*(7), 425-431.

Bunning, K., Smith, C., Kennedy, P., & Greenham, C. (2013). Examination of the communication interface between students with severe to profound and multiple intellectual disability and educational staff during structured teaching sessions. *Journal of Intellectual Disability Research*, *57*(1), 39-52.

Caldwell, P. (2005). *Finding you finding me: Using intensive interaction to get in touch with people whose severe learning disabilities are combined with autistic spectrum disorder*. Jessica Kingsley Publishers.

Caldwell, P. (2006). Speaking the other's language: Imitation as a gateway to relationship. *Infant and Child Development: An International Journal of Research and Practice*, *15*(3), 275-282.

Caldwell, P. (2008). *Using intensive interaction and sensory integration: a handbook for those who support people with severe autistic spectrum disorder*. Jessica Kingsley Publishers.

Calveley, J. (2012). Including adults with intellectual disabilities who lack capacity to consent in research. *Nursing Ethics*, *19*(4), 558-567.

Cambridge, P., & Forrester-Jones, R. (2003). Using individualised communication for interviewing people with intellectual disability: a case study of user-centred research. *Journal of Intellectual and Developmental Disability*, *28*(1), 5-23.

Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, *35*(2), 113-120.

Care Act (2014). London: The Stationery Office

Carter, M., & Iacono, T. (2002). Professional judgments of the intentionality of communicative acts. *Augmentative and Alternative Communication*, *18*(3), 177-191.

Cascella, P. W. (2005). Expressive communication strengths of adults with severe to profound intellectual disabilities as reported by group home staff. *Communication Disorders Quarterly*, *26*(3), 156-163.

Cascella, P. W., & McNamara, K. M. (2005). Empowering students with severe disabilities to actualize communication skills. *Teaching Exceptional Children*, *37*(3), 38-43.

Chadwick, D. D., Jolliffe, J., & Goldbart, J. (2003). Adherence to eating and drinking guidelines for adults with intellectual disabilities and dysphagia. *American Journal on Mental Retardation*, *108*(3), 202-211.

Charpentier, A., Morgan, S., & Harding, C. (2018). A service evaluation of parent adherence with dysphagia management therapy guidelines: reports from family carers supporting children with complex needs in Greece. *Disability and rehabilitation*, 1-8.

Chatwin, J. (2014). Conversation analysis as a method for investigating interaction in care home environments. *Dementia*, *13*(6), 737-746.

Clark, H. (2006) Social actions, social commitments. In N.J. Enfield & S.C. Levinson (Eds.)., *Roots of humans sociality: Culture cognition and interaction* (pp.126-150). Oxford: Berg.

Clayman, S. (2014) Turn Allocation and Turn Sharing. In J. Sidnell and T. Stivers (Eds.)., *The Handbook of Conversation Analysis.* pp. 150 – 166. Sussex: Wiley-Blackwell.

Clayman, S. E., & Heritage, J. (2014). Benefactors and beneficiaries. *Requesting in Social Interaction*, *26*, 55.

Clegg, J. A., Standen, P. J., & Cromby, J. J. (1991). Interactions between adults with profound intellectual disability and staff. *Australia and New Zealand Journal of Developmental Disabilities*, *17*(4), 377-389.

Cornish , K. & Bramble D (2002) Cri du Chat syndrome: Genotype–phenotype correlations and recommendations for clinical management. *Developmental Medicine and Child Neurology 44(7) 494-7*

Costello, B. A., & Roberts, F. (2001). Medical recommendations as joint social practice. *Health Communication*, *13*(3), 241-260.

Coupe O'Kane, J. and Goldbart, J. (1998) *Communication Before Speech: Development and Assessment*, (2nd ed). London: David Fulton.

Craik, K. H., Lampert, M. D., & Nelson, A. J. (1996). Sense of humor and styles of everyday humorous conduct. *Humor-International Journal of Humor Research*, *9*(3-4), 273-302.

Crawford, H., Leslie, P., & Drinnan, M. J. (2007). Compliance with dysphagia recommendations by carers of adults with intellectual impairment. *Dysphagia*, *22*(4), 326-334.

Department of Health (2015) *No Voice Unheard, No Right Ignored.* London: The Stationery Office.

Department of Health. (2001). *Valuing people A new strategy for learning disability for the 21st century: A white paper* London: The Stationery Office.

Department of Health. (2009). *Our Health, Our Care, Our Say.* London: The Stationery Office.

Department of Health. (2009). *Valuing people now: A new three-year strategy for people with learning disabilities*. London: The Stationery Office.

Deprivation of Liberty Act (2007): London: The Stationery Office

Dillner, L. (2017). *Is eating too quickly bad for you?.* Available: https://www.theguardian.com/lifeandstyle/2017/nov/20/is-eating-food-too-quickly-bad-for-health. Last accessed 20th November 2018.

Dobson, C., (2008) Conducting research with people not having the capacity to consent to their participation *British Psychological Society Professional Practice Board*

Dobson, S., Upadhyaya, S., Conyers, I., & Raghavan, R. (2002). Touch in the care of people with profound and complex needs: A review of the literature. *Journal of Learning Disabilities*, *6*(4), 351-362.

Drever, E. (1995). *Using semi-structured interviews in small-scale research. A teacher's guide.* Edinburgh: Scottish council for research in education.

Drew, P. (2014) Turn Design. In J. Sidnell and T. Stivers (Eds.)., *The Handbook of Conversation Analysis.* pp. 131 – 149. Sussex: Wiley-Blackwell.

Drew, P. (2005). Conversation analysis. *Handbook of language and social interaction*, 71-102.

Drysdale, H. (2011). Effects of Intensive Interaction on the Social and Communication Behaviour of Three Students with Profound/Multiple Disabilities. (Doctoral dissertation). Retrieved from http://hdl.handle.net/10063/1730

Duncan, D., Matson, J. L., Bamburg, J. W., Cherry, K. E., & Buckley, T. (1999). The relationship of self-injurious behavior and aggression to social skills in persons with severe and profound learning disability. *Research in Developmental Disabilities*, *20*(6), 441-448.

Elgie, S., & Maguire, N. (2001). Intensive interaction with a woman with multiple and profound disabilities: A case study. *Tizard Learning Disability Review*, *6*(3), 18-24.

Ferm, U., Ahlsén, E., & Björck-åkesson, E. (2005). Conversational topics between a child with complex communication needs and her caregiver at mealtime. *Augmentative and Alternative Communication*, *21*(1), 19-41.

Ferm, U., Ahlsén, E., & Björck-Åkesson, E. (2012). Patterns of communicative interaction between a child with severe speech and physical impairments and her caregiver during a mealtime activity. *Journal of Intellectual and Developmental Disability*, *37*(1), 11-26.

Filipi, A. (2009). *Toddler and parent interaction: The organisation of gaze, pointing and vocalisation* (Vol. 192). John Benjamins Publishing.

Finlay, W.M.L., & Antaki, C., (2012) How staff pursue questions to adults with intellectual disabilities *Journal of Intellectual Disability Research 56(4) 361-70*

Finlay, W. M. L., Antaki, C., & Walton, C. (2007). On not being noticed: Intellectual disabilities and the nonvocal register. *Intellectual and Developmental Disabilities*, *45*(4), 227-245.

Finlay, W. M. L., Antaki, C., & Walton, C. (2008). Saying no to the staff: an analysis of refusals in a home for people with severe communication difficulties. *Sociology of health & illness*, *30*(1), 55-75.

Finlay, W. M., Antaki, C., Walton, C., & Stribling, P. (2008). The dilemma for staff in 'playing a game' with a person with profound intellectual disabilities: Empowerment, inclusion and competence in interactional practice. *Sociology of Health & Illness*, *30*(4), 531-549.

Finlay, W.M.L., Walton, C., & Antaki, C (2011) Giving feedback to care staff about offering choices to people with intellectual disabilities: *Applied Conversation Analysis, pp 161 -183*

Firth, G., Elford, H., Leeming, C., & Crabbe, M. (2008). Intensive interaction as a novel approach in social care: care staff's views on the practice change process. *Journal of Applied Research in Intellectual Disabilities*, *21*(1), 58-69.

Fitzgerald, P., (2017) Therapy Talk, Conversation analysis in practice therapy: Improving aphasic conversation. *Research on Language and Social Interaction* 47; 3; 219-238

Foreman, P., Arthur-Kelly, M., & Pascoe, S. (2007). The impact of partner training on the communicative involvement of students with multiple and severe disability in special schools. *Journal of Intellectual and Developmental Disability*, *32*(4), 233-247.

Forrester, M., & Ramsden, C.A (2000) Discursive ethnomethodology: Analysing power and resistance in talk, *Psychology, Crime & Law, 6(4), 281-304*

Forrester-Jones, R., Jones, S., Heason, S., & Di'Terlizzi, M. (2004). Supported employment: a route to social networks. *Journal of Applied Research in Intellectual Disabilities*, *17*(3), 199-208.

Forster, S., & Iacono, T. (2008). Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of intellectual and developmental disability*, *33*(2), 137-147.

Forster, S., & Iacono, T. (2014). The nature of affect attunement used by disability support workers interacting with adults with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, *58*(12), 1105-1120.

Forster, S., Gray, K. M., Taffe, J., Einfeld, S. L., & Tonge, B. J. (2011). Behavioural and emotional problems in people with severe and profound intellectual disability. *Journal of Intellectual Disability Research*, *55*(2), 190-198.

Franklin, A., Raws, P., & Smeaton, E. (2015). *Unprotected, overprotected: Meeting the needs of young people with learning disabilities who experience, or are at risk of, sexual exploitation*. Barnardo's. Available: http://www.barnardos.org.uk/cse_learning_and_disability_policy_briefing_paper_england.pdf. Last accessed 20th November 2018.

Fuller, M., Healey, M., Bradley, A.,Hall, T. (2004) Barriers to learning: a systematic study of the experience of disabled students in one university. *Studies in Higher Education(29) 303-318*

Garfinkel, H. (1967). *Studies in ethnomethodology.* Prentice-Hall: Englewood Cliffs.

Gast, D. L., & Ledford, J. R. (2009). *Single-subject research methodology in behavioral sciences* London: Routledge.

Gelling (2004) Informed Consent in Health and Social Care Research : RCN Guidance for Nurses *Royal College of Nursing*

Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(3), 192-199.

Glover, G., Williams, R., Heslop, P., Oyinlola, J., & Grey, J. (2017). Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*, *61*(1), 62-74.

Goffman, E. (1959) *The Presentation of Self in Everyday Life*. Garden City: Doubleday.

Goffman, E. (1983). The interaction order: American Sociological Association, 1982 presidential address. *American sociological review*, *48*(1), 1-17.

Gomez, M. T. (2012). The S words: sexuality, sensuality, sexual expression and people with intellectual disability. *Sexuality and disability*, *30*(2), 237-245.

Goode, D. (1994). *A world without words: The social construction of children born deaf and blind*. Temple University Press: Philadelphia

Goode, D. (2010). *A world without words: The social construction of children born deaf and blind* Philadelphia: Temple University Press.

Goodwin, C. (1980). Restarts, pauses, and the achievement of a state of mutual gaze at turn-beginning. *Sociological inquiry*, *50*(3-4), 272-302.

Goodwin, C., (1981) *Conversational organization: Interaction between speakers and hearers.* New York: Academic Press

Green, C. W., & Reid, D. H. (1996). Defining, validating, and increasing indices of happiness among people with profound multiple disabilities. *Journal of Applied Behavior Analysis*, *29*(1), 67-78.

Grieser, D. L., & Kuhl, P. K. (1988). Maternal speech to infants in a tonal language: Support for universal prosodic features in motherese. *Developmental psychology*, *24*(1), 14.

Griffiths, C., & Smith, M. (2016). Attuning: a communication process between people with severe and profound intellectual disability and their interaction partners. *Journal of Applied Research in Intellectual Disabilities*, *29*(2), 124-138.

Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of applied research in intellectual disabilities*, *12*(3), 190-203.

Guthrie, K., & Beadle-Brown, J. (2006). Defining and measuring rapport: Implications for supporting people with complex needs. *Tizard Learning Disability Review, 11*(3), 21-30.

Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice*. Routledge.

Harding, C., & Cockerill, H. (2015). Managing eating and drinking difficulties (dysphagia) with children who have learning disabilities: What is effective?. *Clinical child psychology and psychiatry*, *20*(3), 395-405.

Harding, C., Wade, C., & Harrison, K. (2013). Communication between children and carers during mealtimes. *Journal of Research in Special Educational Needs*, *13*(4), 242-250.

Hatton, C. (2014) *How does research have an impact on daily lives of people with learning disabilities.* Seattle Club Conference 2014. Canterbury. Slides available at: https://www.slideshare.net/JusticeforLB/chris-hatton-keynote-seattle-club-2014 . Last accessed 20th November 2018.

Hayano, K. (2014) Question Design in Conversation. In J. Sidnell and T. Stivers (Eds.)., *The Handbook of Conversation Analysis*. pp. 395 - 415. Sussex: Wiley-Blackwell.

Healy, D., & Walsh, P. N. (2007). Communication among nurses and adults with severe and profound intellectual disabilities: Predicted and observed strategies. *Journal of Intellectual Disabilities : 11*(2), 127-141.

Heath, C., & Luff, P. (2014) Embodied Action and Organizational Activity In J.Sidnell & T Stivers: The handbook of conversational analysis. London:Wiley Blackwell

Heath, C. (1985). The consultation's end: The coordination of speech and body movement. *International Journal of the Sociology of Language*, *1985*(51), 27-42.

Heath, C. (1986). *Body movement and speech in medical interaction*. Cambridge: Cambridge University Press.

Heath, C., Hindmarsh, J., & Luff, P. (2010). *Video in qualitative research*. London: Sage Publications.

Helfrich-Miller, K. R., Rector, K. L., & Straka, J. A. (1986). Dysphagia: its treatment in the profoundly retarded patient with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, *67*(8), 520-525.

Heritage, J., (1988) Explanations as Accounts: A conversation analytical approach; in Charles Antaki: Analyzing Lay Explanation: A Case Book of Methods. London, Sage, pp127- 144

Heritage, J., (1998) Conversation Analysis and Institutional Talk: Analyzing Distinctive Turn-Taking Systems; In S.Cmejrková, J.Hoffmannová, O.Müllerová and J.Svetlá (1998) (eds.) *Proceedings of the 6th International Congresss of IADA (International Association for Dialog Analysis)*, Tubingen: Niemeyer, pp.3-17.

Heritage, J., (2003) Presenting Emanuel Schegloff. In Carlo Prevignano and Paul Thibault (eds.), *Discussing Conversation Analysis: Emanuel Schegloff*. Amsterdam: Benjamins, 2003: 1-10.

Heritage, J. (2003) Designing questions and setting agendas in the news interview. In P. Glenn, C Lebaron & J.Mandelbaum (Eds.) *Studies in language and social interaction* (pp. 57-90). Mahwah, New Jersey: Lawrence Erlbaum.

Heritage, J. (2010). Questioning in medicine. *Why do you ask*, 42-68.

Hewett, D. (2007). Do touch: Physical contact and people who have severe, profound and multiple learning difficulties. *Support for Learning, 22*(3), 116-123.

Hoey, E.M., (2017) Sequence recompletion: A practice for managing lapses in conversation *Journal of Pragmatics, 7,* 47-63

Hogg, M. A., & Vaughan, G. M. (1995). *Social psychology: An introduction*. Harvester Wheatsheaf.

Hostyn, I., & Maes, B. (2009). Interaction between persons with profound intellectual and multiple disabilities and their partners: A literature review. *Journal of Intellectual and Developmental Disability*, *34*(4), 296-312.

Hostyn, I., Petry, K., Lambrechts, G., & Maes, B. (2011). Evaluating the quality of the interaction between persons with profound intellectual and multiple disabilities and direct support staff: A preliminary application of three observation scales from parent–infant research. *Journal of Applied Research in Intellectual Disabilities, 24*(5), 407-420.

Hughes, R. P., Redley, M., & Ring, H. (2011). Friendship and adults with profound intellectual and multiple disabilities and English disability policy. *Journal of Policy and Practice in Intellectual Disabilities*, *8*(3), 197-206.

Hurman, M. (2014). *Developing Indicators of a Rapport Measure.* Available: http://www.kent.ac.uk/tizard/research/research_projects/Centre%20study%20posters%202013/IRM%20Centre%20Study%20Week%20Poster_mh.pdf. Last accessed 1st May 2015.

Hutchby, I., & Wooffitt, R. (1998). *Conversation Analysis: Principles, practice and applications.* Cambridge: Polity.

Hutchby, I., & Wooffitt, R. (2008) *Conversation Analysis.* Cambridge: Polity

Iacono, T., & Murray, V. (2003). Issues of informed consent in conducting medical research involving people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *16*(1), 41-51.

Iacono, T., Carter, M., & Hook, J. (1998). Identification of intentional communication in students with

Ineson, R. (2015). Exploring paid employment options with a person with severe learning disabilities and high support needs: An exploratory case study. *British Journal of Occupational Therapy*, *78*(1), 58-65.

Jackson, C., Land, V., & Holmes, E. J. (2017). Healthcare professionals' assertions and women's responses during labour: A conversation analytic study of data from One born every minute. *Patient education and counselling*, *100*(3), 465-472.

Jefferson, G. (1973). A case of precision timing in ordinary conversation: Overlapped tag-positioned address terms in closing sequences. *Semiotica*, *9*(1), 47-96.

Jefferson, G. (2004). Glossary of transcript symbols with an introduction. *Pragmatics and Beyond New Series*, *125*, 13-34.

Jenkins, L., & Hepburn, A. (2015). Children's sensations as interactional phenomena: A conversation analysis of children's expressions of pain and discomfort. *Qualitative Research in Psychology*, *12*(4), 472-491.

Jingree, T., Finlay, W. M. L., & Antaki, C. (2006). Empowering words, disempowering actions: an analysis of interactions between staff members and people with learning disabilities in residents' meetings. *Journal of Intellectual Disability Research*, *50*(3), 212-226.

Jingree, T., & Finlay, W. M. L. (2013). Expressions of dissatisfaction and complaint by people with learning disabilities: A discourse analytic study. *British Journal of Social Psychology*, *52*(2), 255-272.

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2010). The pearl in the middle: A case study of social interactions in an individual with a severe intellectual disability. *Journal of Intellectual and Developmental Disability*, *35*(3), 175-186.

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012). A model of processes that underpin positive relationships for adults with severe intellectual disability. *Journal of Intellectual and Developmental Disability*, *37*(4), 324-336.

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012). Social interaction with adults with severe intellectual disability: Having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities*, *25*(4), 329-341

Jones, F., Pring, T., & Grove, N. (2002). Developing communication in adults with profound and multiple learning difficulties using objects of reference. *International journal of language & communication disorders*, *37*(2), 173-184.

Kamstra, F.,van der Putten, S., Maes, B., & Vlaskamp, F.J. (2017) Efforts to increase social contact in persons with profound intellectual and multiple disabilities: Analysing individual support plans in the Netherlands *Journal of Intellectual Disabilities* *21(2)*, 1-10.

Kellett, M. (2003). Jacob's journey: developing sociability and communication in a young boy with severe and complex learning difficulties using the Intensive Interaction teaching approach. *Journal of Research in Special Educational Needs*, *3*(1), 1-10.

Kellett, M. (2004). Intensive interaction in the inclusive classroom: using interactive pedagogy to connect with students who are hardest to reach. *Westminster Studies in Education*, *27*(2), 175-188.

Kellett, M. (2005). Catherine's legacy: social communication development for individuals with profound learning difficulties and fragile life expectancies. *British Journal of Special Education*, *32*(3), 116-121.

Kendon, A. (1967). Some functions of gaze-direction in social interaction. *Acta psychologica*, *26*, 22-63.

Kendon, A. (2004). *Gesture: Visible action as utterance*. Cambridge University Press.

Kendrick, K (2017) Using Conversation Analysis in the Lab, *Research on Language and Social Interaction*, *50*(1), 1-11.

Kennedy, M., McCombie, L., Dawes, P., McConnell, K. N., & Dunnigan, M. G. (1997). Nutritional support for patients with intellectual disability and nutrition/dysphagia disorders in community care. *Journal of Intellectual Disability Research*, *41*(5), 430-436.

Kent, A. (2011). *Directing dinnertime: Practices and resources used by parents and children to deliver and respond to directive actions* (Doctoral dissertation). Retrieved from https://dspace.lboro.ac.uk/2134/8960

Kent, A. (2012). Compliance, resistance and incipient compliance when responding to directives. *Discourse Studies*, *14*(6), 711-730.

Kidwell, M. (2006) 'Calm down!' the role of gaze in the interactional management of hysteria by the police. *Discourse Studies*, 8(6), 745-770.

Kidwell, M., (2009). Gaze shift as an interactional resource for very young children. *Discourse processes*, *46*(2-3), 145-160.

Kidwell, M., (2011) Epistemics and embodiment in the interactions of very young children In T Stivers, J Steensig & L Mondada (Eds*). The morality of knowledge in conversation (pp 29-57).* Cambridge: Cambridge University Press

Kidwell, M. (2014) Interaction among Children. In J. Sidnell and T. Stivers (Eds.)., *The Handbook of Conversation Analysis*. pp. 511 – 532. Sussex: Wiley-Blackwell.

Kidwell, M., & Zimmerman, D. H. (2007). Joint attention as action. *Journal of Pragmatics*, *39*(3), 592-611.

Kitzinger, C. (2000). How to resist an idiom. *Research on language and social interaction*, *33*(2), 121-154.

Kitzinger, C. (2014) Repair. In J. Sidnell and T. Stivers (Eds*.). The Handbook of Conversation Analysis*. pp. 229 – 256. Sussex: Wiley-Blackwell.

Knox, M., & Hickson, F. (2001). The meanings of close friendship: The views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *14*(3), 276-291.

Lai, R., Elliott, D., & Ouellette-Kuntz, H. (2006). Attitudes of research ethics committee members toward individuals with intellectual disabilities: The need for more research. *Journal of Policy and Practice in Intellectual Disabilities*, *3*(2), 114-118.

Lambrechts, G., Kuppens, S., & Maes B. (2009) Staff variables associated with the challenging behaviour of clients with severe or profound intellectual disabilities, *Journal of Intellectual Disability Research,* 53, July, pp620-632.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology*, *3*(2), 102-120.

Leaning, B., & Watson, T. (2006). From the inside looking out–an intensive interaction group for people with profound and multiple learning disabilities. *British Journal of Learning Disabilities, 34*(2), 103-109.

LeCompte, M. D., & Schensul, J. J. (1999). *Analyzing & interpreting ethnographic data*. Rowman Altamira.

LeCompte, M. D., & Schensul, J. J. (2010). *Designing and conducting ethnographic research: An introduction* (Vol. 1). Rowman Altamira

Lee, J. (2014). A phenomenological study of the interpersonal relationships between five music therapists and adults with profound intellectual and multiple disabilities. *Qualitative Inquires in Music Therapy: A Monograph Series, 9*, 43-86.

Lerner, G. H., & Zimmerman, D. H. (2003). Action and the appearance of action in the conduct of very young children. *Studies in language and social interaction*, 441-457.

Lerner, G. H., Zimmerman, D. H., & Kidwell, M. (2011). Formal structures of practical tasks: A resource for action in the social life of very young children. *Embodied interaction: Language and body in the material world*, 44-58.

Leuder, I & Fraser, W. (1985). How to keep quiet: Some withdrawal strategies in mentally handicapped adults. Journal of Mental Deficiency Research, 29, 315-330.

Levelt, W. (1989) *Speaking: From intention to articulation*. Cambridge, MA: MIT press

Levinson, S. (2014) Action Formation and Ascription In J. Sidnell and T. Stivers (Eds.)., *The Handbook of Conversation Analysis.* pp. 103 – 130. Sussex: Wiley-Blackwell.

Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, *53*(5), 463-473.

Lovell D., Jones R. & Ephraim G. (1998) The effect of intensive interaction on the sociability of a man with severe intellectual disabilities. *The International Journal of Practical Approaches to Disability,* 22, 3–8.

Luff, P., & Heath, C. (2015) Transcribing Embodied Action. In D. Schiffrin, D. Tannen & H. Hamilton (Eds) *The Handbook of Discourse Analysis*, 367-390. London:Wiley-Blackwell.

Lytra, V. (2007) Teasing in contract encounters: Frames, participant positions and responses*. Multilingual-Journal of Cross-Cultural and Interlanguage Communication, 26(4), 381-408.*

MacMartin, C., (2008) Resisting optimistic questions in narrative and solution-focused therapies. In A Perakyla, C.antaki, S.Vehvilhainen & I. Leudar (Eds.) *Conversation analysis and psychotherapy (pp 89-90)*

Maes, B., Lambrechts, G., Hostyn, I., & Petry, K. (2007). Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature. *Journal of intellectual and Developmental Disability*, *32*(3), 163-178.

Mandelbaum, J. (1991). Conversational non-cooperation: An exploration of disattended complaints. *Research on Language & Social Interaction*, *25*(1-4), 97-138.

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.

Martin, A. M., O'Connor-Fenelon, M., & Lyons, R. (2010). Non-verbal communication between nurses and people with an intellectual disability: a review of the literature. *Journal of Intellectual Disabilities*, *14*(4), 303-314.

Martin, A. M., Connor-Fenelon, M. O., & Lyons, R. (2012). Non-verbal communication between registered nurses intellectual disability and people with an intellectual disability: An exploratory study of the nurse's experiences. part 1. *Journal of Intellectual Disabilities,16*(1), 61-75.

Mathisen, B., (2001) Dysphagia and early language development, *Australian Communication Quarterly,* 3 (1), 7-9.

Matson, J. L., Cooper, C., Malone, C. J., & Moskow, S. L. (2008). The relationship of self-injurious behavior and other maladaptive behaviors among individuals with severe and profound intellectual disability. *Research in Developmental Disabilities*, *29*(2), 141-148.

Mattie, H. D., & Kozen, A. A. (2007). Consideration of behavior states and patterns in IEP development and daily planning: A multiple case study approach involving students with multiple disabilities. *Education and Training in Developmental Disabilities, 42*(1), 38-47.

McConkey, R., Morris, I., & Purcell, M. (1999). Communications between staff and adults with intellectual disabilities in naturally occurring settings. *Journal of Intellectual Disability Research*, *43*(3), 194-205.

McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(1), 27-39.

McDonald, K. E., Keys, C. B., & Henry, D. B. (2008). Gatekeepers of science: attitudes toward the research participation of adults with intellectual disability. *American Journal on Mental Retardation*, *113*(6), 466-478.

McHoul, A. & Luke, A. (1989). The discourses and politics of 'education' and 'epistemology'. *Social Epistemology*. *3*(1), 3-17

McLaughlin, D., & Carr, E. G. (2005). Quality of rapport as a setting event for problem behavior: Assessment and intervention. *Journal of Positive Behavior Interventions*, *7*(2), 68-91.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006). 'I Get by with a Little Help from my Friends': Adults with Intellectual Disability Discuss Loneliness 1. *Journal of Applied Research in Intellectual Disabilities*, *19*(2), 191-203.

Mencap (2004) *Treat Me Right.* London: Mencap

Mencap (2007) *Death By Indifference*. London: Mencap.

Mencap (2008) *Communicating with people with a learning disability*. London: Mencap.

Mencap (2011) *Involve Me.* London: Mencap.

Mencap (2013) *Raising Our Sights - How-to Communication.* London: Mencap.

Mental Capacity Act (2005) London: The Stationery Office

Mental Capacity Act Code of Practice (2005): London: The Stationery Office

Mental Capacity Act Guidance (2007) London: The Stationery Office.

Meuwese-Jongejeugd, A. (2006) *Hearing Impairment in Adults with an Intellectual Disability: epidemiology and rehabilitation.* Erasmus University: Rotterdam

Monzoni, C. M., Duncan, R., Grünewald, R., & Reuber, M. (2011). Are there interactional reasons why doctors may find it hard to tell patients that their physical symptoms may have emotional causes? A conversation analytic study in neurology outpatients. *Patient education and counseling*, *85*(3), e189-e200.

Morgan, D. L., & Morgan, R. K. (2008). *Single-case research methods for the behavioral and health sciences.* London: Sage Publications.

Morrison, V., & Bennett, P. (2009). *An introduction to health psychology.* London: Pearson Education.

Muntigl, P. (2013). Resistance in couples counselling: Sequences of talk that disrupt progressivity and promote disaffiliation. *Journal of Pragmatics*, *49*(1), 18-37.

Nelson, C., van Dijk, J., McDonnell, A. P., & Thompson, K. (2002). A framework for understanding young children with severe multiple disabilities: The van Dijk approach to assessment. *Research and practice for persons with severe disabilities*, *27*(2), 97-111.

Newman, W., Button, G., & Cairns, P. (2010). Pauses in doctor–patient conversation during computer use: The design significance of their durations and accompanying topic changes. *International journal of human-computer studies*, *68*(6), 398-409.

NHS England. (2012). *Winterbourne View - Time for Change.* Available: https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf. Last accessed 20th November 2018.

NHS Patient Safety Agency (2004) *Understanding the Patient Safety Issues for People with Learning Difficulties.* Available: https://patientsafety.health.org.uk/resources/understanding-patient-safety-issues-people-learning-disabilities   Last accessed: 20th November 2018.

NHS. (2018). *Learning Disabilities.* Available: https://www.nhs.uk/conditions/learning-disabilities/. Last accessed 20th November 2018.

Nicholson, C. (2015) Ethical approval in studies raising consent issues. *Nursing Times*, 111: 3, 18-20.

Nicholson, C. (2017). *Misalignment between the DSM-5 and the Mental Capacity Act.* Available: https://blogs.bmj.com/bmj/2017/03/07/clare-nicholson-misalignment-between-the-dsm-5-and-the-mental-capacity-act/. Last accessed 20th November 2018.

Nijs,S. Penne,A. Vlaskamp,C & Maes,B. (2016) Peer Interactions among Children with Profound Intellectual and Multiple Disabilities during Group Activities. *Journal of Applied Research in Intellectual Disabilities 2016 July29(4) pp366-77*

Nind, M. (1996). Efficacy of intensive interaction: Developing sociability and communication in people with severe and complex learning difficulties using an approach based on caregiver-infant interaction. *European Journal of Special Needs Education, 11*(1), 48-66.

Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. National Centre for Research Methods p24*

Nind, M., & Hewett, D. (2001). *A practical guide to intensive interaction* Worcestershire: British Institute of Learning Disabilities.

Nind, M., & Hewett, D. (2012). *Access to communication: Developing the basics of communication with people with severe learning difficulties through intensive interaction* London: Routledge.

No Secrets (1999) : guidance on developing and implementing multi agency policies and procedures to protect vulnerable adults from abuse: Lord Chancellor's Department: The Stationery Office

Nordgren, L. (2010). Mostly *empty* words-what the discourse of "choice" in health care does. *Journal of Health Organization and Management, 24*(2), 109-126.

Nurenberg Code of Ethical Practice 1949; *Office for Human Research Protections*

O'Reilly, K., (2009)*. For interdisciplinarity and a disciplined, professional sociology. Innovation: The European Journal of Social Science Research, 22 (2), 219-232*

O'Reilly, K. (2012). *Ethnographic methods* (2nd Ed). Abingdon: Routledge.

O'Reilly, K.. (2015). *Reflexity.* Available: https://karenoreilly.wordpress.com/what-is-ethnography/reflexivity/. Last accessed 20th November 2018.

Ochs, E. (1979). Transcription as theory. In E. Ochs and B. Schieffelin (Eds.) *Developmental pragmatics*. (pp. 43-72). New York: Academic Press.

Ogden, J. (2012). *Health Psychology: A Textbook: A textbook*. McGraw-Hill Education (UK).

Oliver M (1983) *Social Work with Disabled People*. Basingstoke: MacMillan,

Oliver M (1990) *The Politics of Disablement* Basingstoke: MacMillan

Olsson, C. (2005). The use of communicative functions among pre-school children with multiple disabilities in two different setting conditions: Group versus individual patterns. *Augmentative and Alternative Communication*, *21*(1), 3-18.

Oxford English Dictionary (2018) Available: www.oed.com. Last accessed: 20th November 2018.

Pahl, R. E. (2000). *On friendship*. Cambridge: Polity Press.

Parkin, Kennedy, Bate, Long Hubble & Powell (2018) House of Commons Briefing Paper 07058

Parry, R. (2015) *Semantic Reviewing – A way to get CA findings used in policy and practice.* 3rd EMCA Doctoral Network Meeting - Keynote presentation. Nottingham.

Parsons, T. (1937). The structure of social action. *Sociology. Thought and Action*, *1*(1), 32-46.

Peräkylä, A., & Ruusuvuori, J. (2006). Facial expression in an assessment. In*Video analysis methodology and methods: qualitative audiovisual data analysis in sociology*. Peter Lang: Frankfurt

Perez, C. M., Ball, S. L., Wagner, A. P., Clare, I. C., Holland, A. J., & Redley, M. (2015). The incidence of healthcare use, ill health and mortality in adults with intellectual disabilities and mealtime support needs. *Journal of Intellectual Disability Research*, *59*(7), 638-652.

Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, *18*(1), 35-46.

Pilesjo, M.S. (2014). Creating meaning through the coordination of gaze direction and arm/hand movement *Journal of Interaction Research in Communication Disorders, 5 (1), 63-96*

Pomerantz, A. (1984). Agreeing and disagreeing with assessments: Some features of preferred/dispreferred turn shaped. *University at Albany, State University of New York Scholars Archive*

Pomerantz, A. & Heritage, J. (2014) Preference. In J. Sidnell and T. Stivers (Eds*.)., The Handbook of Conversation Analysis.* pp. 210 – 228. Sussex: Wiley-Blackwell.

Porter, J., Ouvry, C., Morgan, M., & Downs, C. (2001). Interpreting the communication of people with profound and multiple learning difficulties. *British Journal of Learning Disabilities*, *29*(1), 12-16.

Profound and Multiple Learning Disability Network (2003) *Valuing People with Profound and Multiple Learning Disabilities (PMLD)*. Available at: http://www.complexneeds.org.uk/modules/Module-4.2-Safeguarding---privacy,-dignity-

and-personal-care/All/downloads/m14p050c/valuing_people_with_pmld.pdf. Last accessed 20th November 2018

Profound and Multiple Learning Disability Network. (2015). *A right to be included.* Available: http://www.pmldnetwork.org/what_do_we_want/a_right_to_be_included.htm. Last accessed 1st May 2015

Purandare, A., & Litman, D. (2006, July). Humor: Prosody analysis and automatic recognition for f* r* i* e* n* d* s. In *Proceedings of the 2006 Conference on Empirical Methods in Natural Language Processing* (pp. 208-215). Association for Computational Linguistics. Available: http://www.aclweb.org/anthology/W06-1625 http://www.aclweb.org/anthology/W06-1625. Last accessed 20th November.

Reber, A. (1995) *Penguin Dictionary of Psychology* (2nd Ed) London Penguin Books

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience: An introduction to interpretative phenomenological analysis. The Psychologist, 18 (1), 20-23.

Research Governance Framework for Health and Social Care (2005) National Institute for Health and Care Excellence: Department of Health and Social Care. London: the Stationery Office

Robertson, J., Chadwick, D., Baines, S., Emerson, E., & Hatton, C. (2017). Prevalence of dysphagia in people with intellectual disability: a systematic review. *Intellectual and developmental disabilities*, *55*(6), 377-39

Robinson, J. (2014) Overall Structural Organisation. In J. Sidnell and T. Stivers (Eds.). *The Handbook of Conversation Analysis.* pp. 257 – 280. Sussex: Wiley-Blackwell.

Rossano, F., Brown, P., & Levinson, S. C. (2009). Gaze, questioning and culture. *Conversation analysis: Comparative perspectives*, 187-249.

Rossano, F. (2014) Gaze in Conversation. In J. Sidnell and T. Stivers (Eds.)., *The Handbook of Conversation Analysis.* pp. 308 – 329. Sussex: Wiley-Blackwell.

Ruusuvuori, J. (2014) Emotion, Affect and Conversastion. In J. Sidnell and T. Stivers (Eds.)., *The Handbook of Conversation Analysis*. pp. 330 – 349. Sussex: Wiley-Blackwell.

Ruusuvuori, J., & Peräkylä, A. (2009). Facial and verbal expressions in assessing stories and topics. *Research on Language and Social Interaction*, *42*(4), 377-394.

Sacks, H. (1967) The search for help: No one to turn to. In E. Schneidman (Ed.), *Essays in self-destruction* (pp.203-223). New York: Science House.

Sacks, H. (1973). Current research in conversation analysis: The Preference for agreement. *Summer Institute for Linguistics, Ann Arbor, Michigan. Google Scholar*.

Sacks, H. (1984) Notes on methodology. In J. M. Atinkson & J. Heritage (Eds.) *Structure of social action: Studies in conversation analysis.* (pp.413-429). Cambridge: Cambridge University Press.

Sacks, H. (1989) *Seeing Voices.* Los Angeles: University of California Press.

Sacks, H., Schegloff, E.A., & Jefferson, G., (1974) A Simplest Systematics for the Organization of Turn-Taking for Conversation. *Language* Vol. 50, No. 4, Part 1 (Dec., 1974), pp. 696-735

Saldert, C., Johansson, C. and Wilkinson, R. (2015) An interaction-focused intervention approach to training everyday communication partners: a single case study. *Aphasiology* , 29 (3). pp. 378-399.

Samuel, J., Nind, M., Volans, A., & Scriven, I. (2008). An evaluation of Intensive Interaction in community living settings for adults with profound intellectual disabilities. *Journal of Intellectual Disabilities*, *12*(2), 111-126.

Samuels, R., & Chadwick, D. D. (2006). Predictors of asphyxiation risk in adults with intellectual disabilities and dysphagia. *Journal of intellectual disability research*, *50*(5), 362-370.

Sandlund, E. (2004). *Feeling by doing: The social organization of everyday emotions in academic talk-in-interaction* (Doctoral dissertation), Institutionen för kultur och kommunikation.

Schalock, R. L., Luckasson, R. A., & Shogren, K. A. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and developmental disabilities*, *45*(2), 116-124.

Schegloff, E. A. (1968). Sequencing in conversational openings1. *American anthropologist*, *70*(6), 1075-1095.

Schegloff, E. A., Jefferson, G., & Sacks, H. (1977). The preference for self-correction in the organization of repair in conversation. *Language*, *53*(2), 361-382.

Schegloff, E. A. (1984). On some gesture's relation to talk. *Structures of social action: Studies in conversation analysis*, 266-296.

Schegloff, E. A. (1987). Recycled turn beginnings: A precise repair mechanism in conversation's turn-taking organization. *Talk and social organisation*, *1*, 70-85.

Schegloff, E. A. (1992). Repair after next turn: The last structurally provided defense of intersubjectivity in conversation. *American journal of sociology*, *97*(5), 1295-1345.

Schegloff, E. A. (1996). Turn organization: One intersection of grammar and interaction. *Studies in interactional sociolinguistics*, *13*, 52-133.

Schegloff, E. A. (2001). Getting serious: Joke→ serious 'no'. *Journal of pragmatics*, *33*(12), 1947-1955.

Schegloff, E. A. (2007). *Sequence organization in interaction: Volume 1: A primer in conversation analysis* (Vol. 1). Cambridge: Cambridge University Press.

Schegloff, E. A., & Sacks, H. (1973). Opening up closings. *Semiotica*, *8*(4), 289-327.

Schuengel, C., Kef, S., Damen, S., & Worm, M. (2010). 'People who need people': attachment and professional caregiving. *Journal of Intellectual Disability Research*, *54*, 38-47.

Schwier, K. M., & Stewart, E. S. (2005). *Breaking Bread, Nourishing Connections: People with and Without Disabilities Together at Mealtime*. Brookes Pub.

Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, *2*, 197-204.

Sidnell, J. (2006). Coordinating gesture, talk, and gaze in reenactments. *Research on Language and Social Interaction*, *39*(4), 377-409.

Sidnell, J., & Stivers, T., (2014). *A Handbook of Conversation Analysis,* London: Wiley-Blackwell

Sigafoos, J. (2000). Communication development and aberrant behavior in children with developmental disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 168-176.

Sigafoos, J., & Meikle, B. (1996). Functional communication training for the treatment of multiply determined challenging behavior in two boys with autism. *Behavior Modification, 20*(1), 60-84.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London: Sage.

Smith, J., & Osborn, M. (2003). Interpretive phenomenological analysis, qualitative psychology. A practical guide to research methods. In J. A. Smith (Eds) *Qualitative Psychology: A Practical Guide to Research Methods* (pp.9-26). London: Sage.

Snell, M. (2002). Using dynamic assessment with learners who communicate nonsymbolically. *Augmentative and Alternative communication*, *18*(3), 163-176.

Snow, D., Anderson,L., Lofland, J., & Lofland L. H. Analysing Social Settings: A Guide to Qualitative Observation and Analysis (2nd Ed) Wadsworth Publishing

Stancliffe, R. J., Harman, A. D., Toogood, S., & McVilly, K. R. (2007). Australian implementation and evaluation of active support. *Journal of Applied Research in Intellectual Disabilities*, *20*(3), 211-227.

Stern, D. N., Hofer, L., Haft, W., & Dore, J. (1985). Affect attunement: The sharing of feeling states between mother and infant by means of inter-modal fluency. *Social perception in infants*, 249-268.

Stivers, T. (2006) Treatment decisions: Negotiations between doctors and parents in acute care encounters. In *Communication in medical care: Interaction between primary care physicians and patients* (pp. 279-312). Cambridge University Press.

Stivers, T. (2007). Alternative recognitionals in person reference. In *Person reference in interaction: Linguistic, cultural, and social perspectives* (pp. 73-96). Cambridge University Press.

Stivers, T. (2014). Sequence organization. In J. Sidnell and T. Stivers (Eds.).,*The Handbook of Conversation Analysis.* pp. 191 - 209 – 166. Sussex: Wiley-Blackwell.

Stivers, T., Enfield, N. J., Brown, P., Englert, C., Hayashi, M., Heinemann, T. & Levinson, S. C. (2009). Universals and cultural variation in turn-taking in conversation. *Proceedings of the National Academy of Sciences*, pnas-0903616106.

Stivers, T., & Sidnell, J. (2005). Introduction: multimodal interaction. *Semiotica*, *2005*(156), 1-20.

Stokoe, E. (2013). The (in) authenticity of simulated talk: comparing role-played and actual interaction and the implications for communication training. *Research on Language & Social Interaction*, *46*(2), 165-185.

Stokoe, E. (2014) *Explaining EMCA to non-academics*. 1st EMCA Doctoral Network Meeting – Keynote presentation. Edinburgh.

Stokoe, E. (2014). The Conversation Analytic Role-play Method (CARM): A method for training communication skills as an alternative to simulated role-play. *Research on Language and Social Interaction*, *47*(3), 255-265.

Stokoe, E., (2016) Calling the GP surgery: patient burden, patient satisfaction, and implications for training. *British Journal of General Practice, 66(652) 779-785*

Streeck, J., Goodwin, C., & LeBaron (2011). Embodied Interaction in the Material World -An Introduction in C. Goodwin & J. Streeck (Eds) *Embodied Interaction, Language and Body in the Material World* (pp 1 – 26) Cambridge: Cambridge University Press.

Tadema, A. C., & Vlaskamp, C. (2010). The time and effort in taking care for children with profound intellectual and multiple disabilities: A study on care load and support. *British Journal of Learning Disabilities*, *38*(1), 41-48.

Ten Have, P., (2007) *Doing conversation analysis: A practical guide (2nd Ed).* London:Sage

Trief, E., Bruce S.M., Cascella, P.W. & Ivy, I.S., (2009) The development of a universal system tangible system . *Journal of Visual Impairment and Blindness 103 (7) 425-430*

Van Splunder, J., Stilma, J. S., Bernsen, R. M., & Evenhuis, H. M. (2004). Prevalence of ocular diagnoses found on screening 1539 adults with intellectual disabilities. *Ophthalmology*, *111*(8), 1457-1463.

Vehvilhainen, S. (2008) Identifying and managing resistance in psychoanalytic interaction. In A. Perakyla, C. antaki, S. Vehvlainen & I.Leudar (Eds.) *Conversation analysis and psychotherapy (pp. 123-138).* Cambridge: Cambridge University Press

Verdonschot, M. M., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research*, *53*(4), 303-318.

Ware, J. E. (2003). Conceptualization and measurement of health-related quality of life: *Archives of physical medical and Rehabilitation 84(2) pp43-51*

Wehmeyer, M. L., & Field, S. L. (2007). *Self-determination: Instructional and assessment strategies*. London: Sage.

Wilkinson, R. (2014) Intervening with Conversation Analysis in speech and language therapy: Improving aphasic conversation. *Research on Language and Social Interaction* 47; 3; 219-238

Williams, V., Ponting, L., Ford, K., and Rudge, P., A bit of common ground': personalisation and the use of shared knowledge in interactions between people with learning disabilities and their personal assistants. *Discourse Studies, 11(5), 607-624.*

Willig, C. (2013). *Introducing qualitative research in psychology*. Brighton: Open University Press.

Willner,P., Bailey, R., Parry R., Dymond., (2010) Evaluation of executive functioning in people with intellectual disabilities. *Journal of Intellectual disability Research, 54*(4), pp 366-379.

Wolf, J., &Jouannou,K. (2017). *Choice Making and Individuals with Significant Disabilities.* Available: https://www.lynchburg.edu/wp-content/uploads/volume-9-2013/JoannnouK-WolfJ-Choice-Making-Significant-Disabilities.pdf. Last accessed 20th November 2018.

World Health Organization (1992). *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines* (Vol. 1). Geneva: World Health Organization.

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.

World Health Organisation & World Bank. (2011). *World report on disability*. Geneva: WHO. Available: http://www.who.int/disabilities/world_report/2011/report.pdf. Last accessed: 20th November 2018.

World Medical Association. (2013). World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *Jama*, *310*(20), 2191.

Ybema, S., Yanow, D., Wels, H., & Kamsteeg, F. H. (Eds.). (2009). *Organizational ethnography: Studying the complexity of everyday life*. London: Sage.

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Appendix A: Research Information Sheet - Staff

Verbal and non-verbal communication with adults with severe to profound learning disabilities: an exploratory investigation using conversation analysis.

What is the purpose of the study?

As part of my PhD at Anglia Ruskin University, I am doing a research study. I want to find out how people with severe to profound learning disabilities communicate with support staff, other professionals, family and friends. My supervisors are Dr Mick Finlay and Dr Steven Stagg.

What will the study involve?

The study will involve being video recorded doing everyday activities with a person/people with severe to profound learning disabilities. These filmed sessions will usually last between 5 minutes and 1 hour. I may also have informal discussions with you about communicating with people with severe to profound learning disabilities.

Why have you been contacted?

I am asking you to take part in this research because you have regular contact in the course of your work at [insert centre name] with people with severe to profound learning disabilities.

Do you have to take part?

No, you do not have to take part. Participation is voluntary. If you choose not to take part, there will not be any repercussions. Your job will not be affected. If you agree to take part in this research, I would check that you are happy to be filmed on each occasion before turning the

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camera on. You are free to say that you do not want to be filmed on any occasion, for any reason. I will also ask you after each filming session whether you are happy for the data to be analysed.

If I decide to take part. can I withdraw?
 If you decide you want to take part, you may still change your mind. You have the right to withdraw from the study at any time.

If you tell me before data collection begins that you no longer wish to take part, then your wishes will be respected and you will not take part in the study. If you change your mind after data collection starts but before [insert date — one month into data collection] then you will take no further part in the study and all your data will be destroyed and not used in the research. If you tell me after [insert same datel that you no longer wish to take part in the study, then again, your wishes will be respected and you will take no further part in the study, but data collected prior to that may be used in the research. This is because the data may already have been analysed and included in a report or paper. However any data collected in the week immediately before you tell me of your wish to withdraw will be destroyed and not used in the research.

What are the possible disadvantages/advantages of taking part?

I don't believe there will be any disadvantages for you if you agree to take part in my research. However, there is a possibility some people may feel uncomfortable by the presence of a researcher and/or camera. There are a number of possible advantages including improved communication with people with severe to profound learning disabilities.

If you take part in the study, you will be able to attend an individual feedback session if you wish but you do not have to attend. Again there will be no repercussions if you choose not to. At this session, which will last up to 45 minutes, you will be able to view footage of yourself interacting with a person or people with severe to profound learning disabilities and have the opportunity to reflect upon and discuss it. There is a possibility that you may feel uncomfortable viewing footage of your own interactions with people with severe to profound learning disabilities. However, I have chosen to offer these sessions as research suggests that viewing and reflecting upon one's own practice improves it.

Will information about you and your involvement in the study be kept confidential?

Information from the study will be kept private. It will not be shared with [insert name of centre] management. The only people who will see your personal data are myself and my supervisors. I will only share your data if there is any information that gives me reason to be worried about anybody's safety. In such cases, the safeguarding procedures of [insert service name]will be followed.

What will happen to the information collected during the research?

I will analyse the data to examine how people with severe to profound learning disabilities and others in their everyday lives communicate. I will make a summary report which I will give to all interested participants in which data will be anonymised. I will also use anonymised examples (where your identity is hidden) in my PhD thesis, in published articles, at conferences, to produce teaching materials. Where video footage is used for these purposes, faces will be blurred, pitch of voice changed and names will be bleeped out.

The data will be kept, stored securely, for six years. This is to allow time to share the findings of this research project with others and to facilitate further analysis of communication with people with severe to profound learning disabilities.

What if there is a problem?

If at any time you want the filming to stop, the camera would be turned off immediately. If there are ever any problems, please contact me. My details are below. If you feel you need to talk to someone else regarding issues with the research, you could contact my supervisor, Dr

Mick Finlay.

Who has reviewed this study?

Approval has been given by the Social Care Research Ethics Committee, Lewisham Research Governance Board and from the Faculty of Science and Technology at Anglia Ruskin University.

Any further queries?

If you need any further information, please do not hesitate to email me, Clare Nicholson, on X. Alternatively, you can reach me by telephone on X

Thank you for taking the time to read this information sheet.

If you agree to take part in this study, please complete the attached consent form and return it to me.

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Appendix B: Non – disabled participants:

Consent Form

Verbal and non-verbal communication with adults with severe to profound learning disabilities: an exploratory investigation using conversation analysis.(Please tick as appropriate)

I have read and understood the information sheet about this

study.

I have had an opportunity to ask questions and discuss
this study and have received satisfactory answers to
any questions I had.

I have received enough information about this study.

I understand my withdrawal rights as set out in the

information sheet provided.

I understand personal data will be securely stored for six years
and may be accessed my Clare Nicholson and her supervisory
team at Anglia Ruskin University.

INVESTORS
IN PEOPLE

I understand the purposes for which data may be used (as set
out in the information sheet).

I consent to taking part in this study.

Signed (participant)	Date
Name in block letters	

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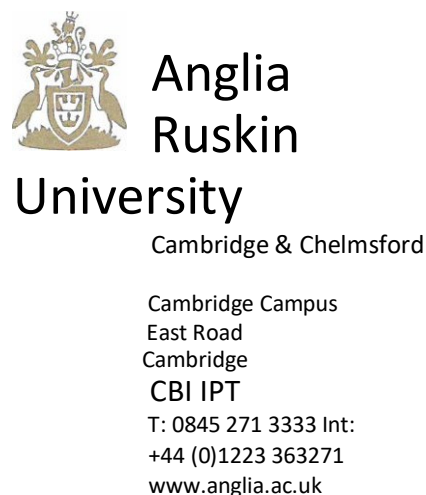
Appendix C: Research Information Sheet — Other Professionals

Verbal and non-verbal communication with adults with severe to profound learning disabilities: an exploratory investigation using conversation analysis.

What is the purpose of the study?

As part of my PhD at Anglia Ruskin University, I am doing a research study. I want to find out how people with severe to profound learning disabilities communicate with support staff, other professionals, family and friends. My supervisors are Dr Mick Finlay and Dr Steven Stagg.

What will the study involve?

The study will involve being video recorded interacting with a person/people with severe to profound learning disabilities. These filmed sessions will usually last between 5 minutes and 1 hour. I may also have informal discussions with you about communicating with people with severe to profound learning disabilities.

Why have you been contacted?

I am asking you to take part in this research because you have regular contact in the course of your work at [insert centre name] with people with severe to profound learning disabilities.

Do you have to take part?

No, you do not have to take part. Participation is voluntary. If you choose not to take part, there

will not be any repercussions. Your contracts with [insert centre name] will not be affected. If you agree to take part in this research, I would check that you are happy to be filmed on each occasion before turning the camera on. You are free to say that you do not want to be filmed on any occasion, for any reason. I will also ask you after each filming session whether you are happy for the data to be analysed.

If I decide to take part. can I withdraw?

 If you decide you want to take part, you may still change your mind. You have the right to withdraw from the study at any time.

If you tell me before data collection begins that you no longer wish to take part, then your wishes will be respected and you will not take part in the study. If you change your mind after data collection starts but before [insert date — one month into data collection] then you will take no further part in the study and all your data will be destroyed and not used in the research. If you tell me after [insert same date] that you no longer wish to take part in the study, then again, your wishes will be respected and you will take no further part in the study, but data collected prior to that may be used in the research. This is because the data may already have been analysed and included in a report or paper However any data collected in the week immediately before you tell me of your wish to withdraw will be destroyed and not used in the research.

What are the possible disadvantages/advantages of taking part?

I don't believe there will be any disadvantages for you if you agree to take part in my research. However, there is a possibility some people may feel uncomfortable by the presence of a researcher and/or camera. There are a number of possible advantages including improved communication with people with severe to profound learning disabilities.

If you take part in the study, you will be able to attend an individual feedback session if you wish but you do not have to attend. Again there will be no repercussions if you choose not to. At this session, which will last up to 45 minutes, you will be able to view footage of yourself interacting with a person or people with severe to profound learning disabilities and have the opportunity to reflect upon and discuss it. There is a possibility that you may feel uncomfortable viewing footage of your own interactions with people with severe to profound learning disabilities. However, I have chosen to offer these sessions as research suggests that viewing and reflecting upon one's own practice improves it.

Will information about you and your involvement in the study be kept confidential?

Information from the study will be kept private. It will not be shared with [insert name of centre] management. The only people who will see your personal data are myself and my supervisors. I will only share your data if there is any information that gives me reason to be worried about anybody's safety. In such cases, the safeguarding procedures of [insert service name] will be followed.

What will happen to the information collected during the research?

I will analyse the data to examine how people with severe to profound learning disabilities and others in their everyday lives communicate. I will make a summary report which I will give to all interested participants in which data will be anonymised. I will also use anonymised examples (where your identity is hidden) in my PhD thesis, in published articles, at conferences, to produce teaching materials. Where video footage is used for these purposes, faces will be blurred, pitch of voice changed and names will be bleeped out.

The data will be kept, stored securely, for six years. This is to allow time to share the findings of this research project with others and to facilitate further analysis of communication with people with severe to profound learning disabilities.

What if there is a problem?

If at any time you want the filming to stop the camera would be turned off immediately. If there are ever any problems, please contact me. My details are below. If you feel you need to talk to someone else regarding issues with the research, you could contact my supervisor, Dr Mick
Finlay (mick.finlay@anglia.ac.uk).

Who has reviewed this study?

Approval has been given by the Social Care Research Ethics Committee, Lewisham Research

Governance Board and from the Faculty of Science and Technology at Anglia Ruskin University.

Anv further queries?

 If you need any further information, please do not hesitate to email me, Clare Nicholson, on X. Alternatively, you can reach me by telephone on X.

Thank you for taking the time to read this information sheet.

If you agree to take part in this study, please complete the attached consent form and return it to me.

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Appendix D: Draft Email to be Forwarded to Family and Friends/Other Professionals

Verbal and non-verbal communication with adults with severe to profound learning disabilities:

an exploratory investigation using conversation analysis.

I am studying for a PhD at Anglia Ruskin University and conducting a research project into communication between people with severe to profound learning disabilities and others. My supervisor is Dr Mick Finlay, also of Anglia Ruskin University.

I have asked (centre manager name) to forward you this email, to introduce me to you without disclosing your personal details to me without your consent.

Some of my research will take place at (centre name) where (person with S-PLD's name), attends regularly/resides. I understand you sometimes spend time at (centre name) with (person with S-PLD's name) and I would like to invite you to participate in the research.
I enclose an information sheet which explains this in more detail. If you have any questions about it please feel free to contact me. I would be happy to talk to you about it.
After you have considered the information sheet and are satisfied that all your questions have been answered, if you are prepared to participate in the research please complete the attached form. If you do not wish to participate in the research, you do not have to take any further action and I am grateful to you for taking the time to consider my request.

If you would rather discuss it with me, we can either talk on the phone or meet in person. I would be happy to answer any questions you may have.

My contact details are:- (insert details).

Yours etc.

Appendix E: Mental Capacity Assessment Form (adapted from Devon, NHS, 2013).
Verbal and non-verbal communication with adults with severe to profound learning

disabilities: an exploratory investigation using conversation analysis.

Name:	Location:
I am completing this assessment form on (date)………………………… because the person named above appears to lack capacity at this time.	

Assessment Context			
What is the nature of the decision? (Details)			

Determination of capacity (This is specific, not general determination) See the Mental Capacity Act Code of Practice.			
Is there an impairment of, or disturbance in, the function of the person's mind or brain?	Permanent impairment ☐	Temporary impairment ☐	None ☐
Details:			
Can the decision be delayed because the person is likely to regain capacity in the near future?	Yes ☐	Not likely to regain capacit☐	Not appropriate to delay ☐
Details:			
1.Person has ability to understand information related to the decision to be made	Yes ☐		No ☐
Details:			
2.Person has ability to retain information related to the decision to be made.	Yes ☐		No ☐
Details:			
3.Person has ability to use or assess the information whilst considering the decision.	Yes ☐		No ☐
Details:			
4.Person has ability to communicate their decision by any means?	Yes ☐		No ☐
Details: state what steps have been taken to achieve communication			

If you have ticked any of the above questions 1-4 as NO then this person lacks capacity at this time.				
What steps have been taken to enable or assist the person to make or be involved in this decision? E.g. visual aids.				
Is there any advance decision relevant to this decision?	Yes	☐	No	☐
Details:				

Name of assessor_____

Job Title/Tole of the assessor

_____

Signature of the assessor_____

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Appendix F: Draft Email to be Forwarded to Potential Consultees

Verbal and non-verbal communication with adults with severe to profound learning disabilities:

an exploratory investigation using conversation analysis.

I am studying for a PhD at Anglia Ruskin University and conducting a research project into communication between people with severe to profound learning disabilities and others. My supervisor is Dr Mick Finlay, also of Anglia Ruskin University.

I have asked (centre manager name) to forward you this email, to introduce me to you without disclosing your personal details to me without your consent.

Some of my research will take place at (centre name) where (person's name), attends regularly/resides. It is not possible for (person's name) to make any decision about whether to take part in this research and so I am writing to you as (centre manager name) has suggested that you know (person's name) well and you may be a person who would be able and willing to be consulted about whether they might take part in this research.

I enclose an information sheet which explains this in more detail. If you have any questions about it please feel free to contact me. I would be happy to talk to you about it.
When you have considered the information sheet and are satisfied that all your questions have been answered, I would be grateful if you could let me know whether you are prepared to act as a consultee for (person's name).

If you are not prepared to act as a consultee for (person name), please either return the form signed to that effect (either electronically or in hard copy), send me an email or give me a telephone call to let me know. I am grateful to you for taking the time to consider my request.
If on the other hand, you are prepared to act as a consultee, please read the information I have provided about the research, what it entails and its aims and objectives. When you have considered it carefully

and are satisfied that you have sufficient information about the research, please let me have your advice about whether in your view, (person's name) would be likely to agree to take part in the research if he/she had the capacity to do so. Please do this by completing the rest of the attached form and returning it to me, either electronically or in hard copy.

If you would rather discuss it with me, we can either talk on the phone or meet in person. I would be happy to answer any questions you may have.

My contact details are:- (insert details).

Yours etc.

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Appendix G: Consultee Information Sheet

Verbal and non-verbal communication with adults with severe to profound learning
disabilities: an exploratory investigation using conversation analysis.

You are being invited to act as a consultee for someone who is unable to make a decision

for themselves, [insert name of person with S-PLD]. You are being asked to advise about this

person's wishes and feelings as to whether they themselves would have wished to join in

with a research project, if they could have made the decision themselves. The purpose of

this information sheet is to help you understand what it means to be a consultee, what the

research involves and why it is being done.

Please take your time to read this information carefully and feel free to ask questions if you
are unclear about anything.

What does it mean to be a consultee?

A consultee is someone who knows a person with a mental incapacity well and is willing
and able to offer an opinion as to what that that person's wishes would have been if
they had the capacity to make the decision for themselves. If you do not want to act as a
consultee, you do not have to. If you are happy to act as a consultee, then please
complete the attached form.

Please note, you are not being asked for your personal views about the research but you are

being asked for your opinion about what [insert name of person with S-PLD]'s wishes would

have been were they able to respond for themselves.

If you believe that this person would not have wanted to take part in this research, then please tell us. This will then be respected. If you advise that the person would wish to participate and your opinion changes during the course of the study, we would respect this and withdraw them from the research. More specific details about withdrawal from the research are provided later.

If you agree to act as a consultee and advise that you believe the person you know with severe to profound learning disabilities would consent to participating in the research if they had the capacity to do so, I would contact you on a monthly basis. I would send you an email once a month to ensure that I was aware of any concerns or problems. Additionally, I may ask for advice on their preferred communication methods.

Why have I been asked to be a consultee?

You are being asked to be a consultee because of your relationship with this person, either as a family member or somebody who knows that person well. .

What is the purpose of the study?

As part of my PhD at Anglia Ruskin University, I am doing a research study. I want to find out how people with severe to profound learning disabilities communicate with support staff, other professionals, family and friends. My supervisors are Dr Mick Finlay and Dr Steven Stagg.

What will the study involve?

The study will involve video recording sessions of people with severe to profound learning disabilities carrying out everyday activities with staff, other professionals, family and friends. These filmed sessions will usually last between 5 minutes and 1 hour. I will not film scenes of a sensitive nature. I will look at social care records to gather information about diagnoses, medication and preferred communication methods. This information should help to put the video recorded sessions into context. Video footage of interactions may be shown to others featuring in the video in feedback sessions at the centre.

Why do I want to involve the person you know?

The research is being carried out at [insert name of centre] where [insert name of person with SPLDI regularly attends/resides.

Do they have to take part?

No, they do not have to take part. If you advise that they would not wish to take part, there will not be any negative consequences. Their care will not be affected and they will not take part in the study.

If I advise that I believe [insert name of person with S-PLDI would wish to take part. can I then withdraw him/her from the study if I believe they would wish to withdraw?

 If you advise that you believe somebody would consent to taking part in the study if they had the capacity to do so, you may still change your mind.

If you tell me before data collection begins that you no longer believe that [insert person's name with S-PLD] would wish to take part, then your opinion will be respected and they will not take part in the study. If you change your mind after data collection starts but before [insert date — one month into data collection] then [insert name of person with S-PLD] will take no further part in the study and all their data will be destroyed and not used in the research. If you tell me after [insert same date] that you believe that [insert name of person with S-PLD] would no longer wish to take part in the study, then again, your opinion will be respected and they will take no further part in the study, but data collected prior to that may be used in the research.

This is because the data may already have been analysed and included in a report or paper. However any data collected in the week immediately before you tell me of your beliefs about their wish to withdraw will be destroyed and not used in the research.

What are the possible disadvantages/advantages of taking part?

There is a risk that participants with severe to profound learning disabilities may sometimes become distressed during the research. I have designed procedures to minimise this risk. These include learning about how each person communicates distress, having regular contact with consultees and stopping filming and leaving the room if there are any signs of distress caused by the presence of a researcher and/or video camera. I will also contact consultees on a monthly basis during the course of the research to see if they believe that the person concerned would still wish to participate in the study. People who appear distressed by being involved in study will take no further part. There are a number of possible advantages including the potential to increase the quality of [insert name of person with S-PLD]'s communication with others. This has the potential to improve quality of life through possible improved quality of care, reduced frustration and/or by reducing the risk of being excluded.

Will information collected during the study be kept confidential?

Information from the study will be kept private. It will not be shared with management of the [insert name of centre]. The only people who will see personal data are myself and my supervisors. I will only share personal data if there is any information that gives me reason to be worried about the safety of anyone in the study. In these cases, the safeguarding procedures of [name of service] will be followed.

I will use information collected during the study for a number of purposes. These are listed below. However, this data will be anonymised. No clues to anyone's identity will be left in the data. Names will be changed in the written data. In the video footage, faces will be blurred, pitch of voice changed and names will be bleeped out.

What will happen to the information collected during the research?

I will analyse the data to find out how people with severe to profound learning disabilities and others in their everyday lives communicate. I will use anonymised examples (where

identities are hidden) in my PhD thesis, in published articles, at conferences, to produce teaching materials.

Staff and other professionals who have regular contact with [insert name of person with S-PLD] will be offered individual feedback sessions. In this session, they will be given the opportunity to view footage of themselves interacting with the participants with severe to profound learning disabilities. This footage will not be anonymised but only those involved in the interaction will be allowed to view the video footage of it.

The data will be kept, stored securely for six years. This is to allow time to share the findings of this research project with others and to facilitate further analysis of communication with people with severe to profound learning disabilities.

What will happen to the results?

 I plan to share my results in the ways listed above. On completion, I will also make a summary report which I will give to all interested participants and consultees.

What if there is a problem?

If problems are ever expressed (verbally or otherwise), filming will stop immediately. If you become aware of any problems, please contact me. My details are listed below. If you feel you need to talk to someone else regarding issues with the research, you could contact my supervisor, Dr Mick Finlay (mick.finlay@anglia.ac.uk).

Who has reviewed this study?

 Approval has been given by the Social Care Research Ethics Committee, Lewisham Research Governance Board (or other centre) and from the Faculty of Science and Technology at Anglia
Ruskin University.

Any further queries?

If you need any further information, please do not hesitate to email me, Clare Nicholson, on X. Alternatively, you can reach me by telephone on X.

Thank you for taking the time to read this information sheet.

If you are happy to act as a consultee, please complete the attached form and return it to me.

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Appendix H: Consultee Declaration Form

Verbal and non-verbal communication with adults with severe to profound learning disabilities: an exploratory investigation using conversation analysis.

	(Please tick as appropriate)
I have read and understood the information contained in the Consultee Information Form about the role of consultees. I agree to be a consultee for_____	

Signed	Date

Name in block letters

(Please tick as appropriate) I have read and understood the information about this study. I have had an opportunity to ask questions and discuss this study and have received satisfactory answers to any questions I had.	

I have received enough information about this study.

- I understand that_____ Social Care records may be accessed to help understand his/her communication difficulties.

I   understand data relating to_____will be securely stored for six years and may be accessed my Clare Nicholson and her supervisory team at Anglia Ruskin University.

I understand the purposes for which data may be used (as set out in the information sheet).

- I believe that_____ would/would not (delete as appropriate) consent to take part in this study, if he/she were able to do so.

I   have read and understood the information provided about withdrawing from the study. I understand that I can request that_____ be withdrawn from the study.

Signed	Date

Name in block letters

Appendix I: Table of participants with severe intellectual disabilities

Name of Participant	Age	Verbal Abilities	Comprehension	Use of eye gaze	Facial expressions	Vocalisations	Communication through movement	Included in this thesis
Simon	32	None	Unclear	Towards objects he wants Variable use otherwise Experiences impaired vision	Scrunches face Opens mouth Grimaces Slight smile	Pants Screams Grunts Long high pitched vocalisations	Leans away from others Rocks wheelchair to move himself away from situations Pushes objects away and reaches and pulls them towards him Drops objects	Yes
Jake	31	None	Unclear	Towards objects he wants When others interact Away from staff members	Scrunches face Grimaces Smiles Opens mouth	Screams Pants Makes noises from his throat Laughs Low deep short vocalisations Elongated high pitched Large variety of vocalisations Cries	Moves away from others Shuffles nearer to people in physiotherapy sessions Pushes people and objects away Reaches and pulls objects towards him	Yes
Jenny	35	None	Simple words in Portuguese	Towards objects and people she wants When others approach	Regularly smiles – to varying degree Reported previous	Pants Laughs Gurgles Long high pitched vocalisations	Leans into others Moves towards objects and people in wheelchair	Yes

				and/or interact with her	use of frowning but does not appear to use now Opens mouth widely	"Happy" Yelps	and when in kneepads Leans into wheelchair and stands when she appears happy/excited Reaches for and pushes away objects Pushes objects away Drops objects	
Pierce	48	Few phrases	Probable understanding of few phrases	Towards objects and people When others interact with him	Smiles Frowns	Blows raspberries Exhales heavily Squeals Cries	Pushes people away Pulls people towards him Leans towards people Reaches for objects and people	Yes
Thomas	42	Variable but declining	Variable but declining	Intense eye gaze used in interaction with others including during difficulties with speech Towards objects to make choices when cannot verbally communicate	Smiles Sadly frowns	Use of speech Low soft "hmm"	Places his hands on others	Yes

Table of Care Staff Participants

Name of Participant	Institution	Role	*Approximate number of years' experience working with people with severe intellectual disabilities	**Involved in extracts presented in this thesis
Luke	Langley	Care Staff and Jenny's Keyworker	7 years	Yes
Emma	Langley	Care Staff	15 years	Yes
Ayse	Langley	Care Staff and one of Jake's Keyworkers	12 years	Yes
Elvis	Langley	Care Staff	2 years	Yes
Eric	Langley	Care Staff and one of Jake's Keyworkers	3 years	Yes
Leah	Langley	Care Staff	6 years	Yes
Tom	Langley	Agency Care Staff	< 1 year	Yes
Amy	Langley	Care Staff	5 years	Yes
Monty	Langley	Care Staff and Simon's Keyworker	7 years	Yes
Baruk	Langley	Care Staff	5 years	Yes
Samantha	Langley	Agency Care Staff	< 1 year	No
Bako	Langley	Agency Care Staff	< 1 year	Yes
Lynn	Langley	Head of severe intellectual disability branch of service	20+ years	No
Dave	Langley	Manager of centre	20+ years	No
Lauren	Daisy Way	Care Staff	8 years	No
Jose	Daisy Way	Volunteer	< 1 year	Yes
Christa	Daisy Way	Masseur	10 years	No
Paminda	Daisy Way	Agency Care Staff	< 1 year	No
Kathleen	Daisy Way	Manager of centre	30 years	No

*Number of years had to be approximate as many staff had taken career breaks, time off to have children and/or started working in related, but significantly different, areas.

** The details of all participants have been provided even if they do not feature in extracts presented in this thesis. Every participant shaped this thesis through informal interviews and observed and filmed extracts which are not detailed here but informed my views and formulation of themes.

Appendix J: Compatibility Mode

Simplified Notes of Jeffersonian CA Transcription System taken from the University of California Website (accessed 2018)

Available at: pages.ucsd.edu/JeffersonianNotation.doc

Jeffersonian Transcription Notation includes the following symbols:

Symbol	Name	Use
[text]	Brackets	Indicates the start and end points of overlapping speech.
=	Equal Sign	Indicates the break and subsequent continuation of a single interrupted utterance.
(# of seconds)	Timed Pause	A number in parentheses indicates the time, in seconds, of a pause in speech.
(.)	Micropause	A brief pause, usually less than 0.2 seconds.
. or ↓	Period or Down Arrow	Indicates falling pitch.
? or ↑	Question Mark or Up Arrow	Indicates rising pitch.
,	Comma	Indicates a temporary rise or fall in intonation.
-	Hyphen	Indicates an abrupt halt or interruption in utterance.
>text<	Greater than / Less than symbols	Indicates that the enclosed speech was delivered more rapidly than usual for the speaker.
<text>	Less than / Greater than symbols	Indicates that the enclosed speech was delivered more slowly than usual for the speaker.
°	Degree symbol	Indicates whisper or reduced volume speech.
ALL CAPS	Capitalized text	Indicates shouted or increased volume speech.
underline	Underlined text	Indicates the speaker is emphasizing or stressing the speech.
:::	Colon(s)	Indicates prolongation of an utterance.
(hhh)		Audible exhalation
? or (.hhh)	High Dot	Audible inhalation
(text)	Parentheses	Speech which is unclear or in doubt in the transcript.
((italic text))	Double Parentheses	Annotation of non-verbal activity.

Jeffersonian Transcription Notation is described in G. Jefferson, "Transcription Notation," in J. Atkinson and J. Heritage (eds), *Structures of Social Interaction*, New York: Cambridge University Press, 1984.

Appendix K: Questions for Research

1. How and why do staff rely on identities to make choices on the behalf of people with severe-profound intellectual disabilities? (e.g. picking black, yellow and green paint because a person is Jamaican or choosing a potato based dish for an Irish person)

2. How do care staff demonstrate that they belong to the same social group? (e.g. discussing maintenance happening to all social housing in the area, bringing in food to share with all other care staff and discussing management)

3. Should people with severe-profound intellectual disabilities be considered religious, even if they seemingly want to engage in activities which do not align with their religion? (e.g. a Jewish person wanting to eat pork)

4. Are people with severe-profound disabilities who are considered more attractive given more attention? Does the attention they are given differ? (e.g. are people who are considered more attractive given more physical contact? Do care staff spend longer talking to them and discussing their well-being with others?)

5. How do, and should, families and care staff approach grooming, such as body hair care, for women with severe-profound intellectual disabilities? If the person with severe-profound intellectual disabilities is not aware of society's (arguably arbitrary) expectations of women – should they be adhered to (particularly if it causes distress)? Is it enforced normalization or dignity? Where do people, and should people, draw the line? Do people attend to this in interactions?

6. Are some people with severe communication difficulties misdiagnosed as having severe intellectual disabilities? If so, how can we recognize this and rectify it?

7. How do people with severe-profound intellectual disabilities respond to grief? What is it like to attend funerals with people with severe-profound intellectual disabilities?

8. How do care staff respond to inappropriate sexual behaviours of people with intellectual disabilities? (e.g. when a person starts to feel their genitals in a public space, such as a living room, comparing the responses "No" or "Stop that" as opposed to "That's for private places")

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Appendix L – Observations Schedule Coding

	00-04	05-09	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	Notes?
Facial expression													
Smiles													
Big Smiles													
Opens Mouth													
Neutral													
Neutral – tongue out													
Scrunches up face													
Cannot see													
Other													
Vocalisation													
Laughs													
Short burst "happy vocal"													
Panting													
Crying													
Happy Wailing													

Grunting													
Screams (a tune)													
Crying													
Genuinely screams													
No vocalisation													
Cannot hear vocalisation													
Other													
Lee's Proximity													
Close													
Close but not visible													
Same room													
Not present													

Appendix M: IPA Table

Thematic Level	Code	Theme 1	Code	Theme 2	Code	Theme 3	Code	Theme 4	Code	Theme 5
Main Themes	1.	Communication	2.	Jenny's Rights	3.	Rapport building	4	Representations of the relationship	5	Benefits and drawbacks
Themes	1.1 1.2 1.3	Appreciation of abilities and limitations "Getting into Jenny's way of communicating" Barriers caused by staff	2.1 2.2 2.3 2.4.	Freedom and choice Responses to behaviours and positive interactions Being Jenny's advocate Difficulties within the team	3.1 3.2 3.3	Relationship qualities Carer qualities Service-user qualities	4.1 4.2	Luke's conflict: professional vs. personal Jenny representation	5.1 5.2 5.3	For Luke For Jenny For others

Categories	1.1.1.	Comprehension (Visual and Portuguese)	All	Mobility	3.1.1	"Positive interaction"	4.1.1	Key worker duties for Cleide (Liase with others and practical issues)	5.1.1.	Denial of negative
	1.1.2.	Production (Non verbal and challenging)	2.1/2.2/2.4	Challenging Behaviour	3.1.2 3.1.3	Frequency Trust and Confidence	4.1.2	Discusses other key clients.	5.1.2 5.1.3	Feeling trapped Struggle with the team
	1.2.1	Non-verbal methods (Vocalisations, challenging behaviours, facial expressions, proximity, physical contact)			3.2.1 3.2.2	Effort Ability	4.1.3 4.2.1	Personal elements for Lee Personal elements for Cleide	5.1.4 5.2.1	Enjoyment Having an advocate
	1.2.2 1.2.3	Using Portuguese			3.2.3 3.3.1	Knowledge Communication	4.2.2	Boundries	5.2.2 5.2.3	Enjoyment Physical contact
	1.2.4 1.3.1	Person-orientated Challenging Behaviour			3.3.2	abilities. Personable			5.2.4	Development and participation
	1.3.2	Lack of adjustments (and responses) Lack of responses							5.3.1 5.3.2.	Learning from Problems meeting institutional goals
									5.3.3.	Emotional difficulties?

Sub-categories							4.2.1.1	Denies emotional element but later acknowledges	5.1.3.1	Briefings ignored
									Related to:	Lack of knowledge and/or training
							4.2.1.2	Warm about her		
							4.2.1.3	Discusses favourites		
							4.2.2.1	Compares to other staff		
								Behaviour demonstrates the relationship		
							4.2.2.2	Questions how much she understands.		
							4.2.2.3			

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Appendix N: Simplified Notes of Jeffersonian CA Transcription System taken from the University of California Website (accessed 2018)

Available at: pages.ucsd.edu/JeffersonianNotation.doc

Jeffersonian Transcription Notation includes the following symbols:

Symbol	Name	Use
[text]	Brackets	Indicates the start and end points of overlapping speech.
=	Equal Sign	Indicates the break and subsequent continuation of a single interrupted utterance.
(# of seconds)	Timed Pause	A number in parentheses indicates the time, in seconds, of a pause in speech.
(.)	Micropause	A brief pause, usually less than 0.2 seconds.
. or ↓	Period or Down Arrow	Indicates falling pitch.
? or ↑	Question Mark or Up Arrow	Indicates rising pitch.
,	Comma	Indicates a temporary rise or fall in intonation.
-	Hyphen	Indicates an abrupt halt or interruption in utterance.
>text<	Greater than / Less than symbols	Indicates that the enclosed speech was delivered more rapidly than usual for the speaker.
<text>	Less than / Greater than symbols	Indicates that the enclosed speech was delivered more slowly than usual for the speaker.
°	Degree symbol	Indicates whisper or reduced volume speech.
ALL CAPS	Capitalized text	Indicates shouted or increased volume speech.
underline	Underlined text	Indicates the speaker is emphasizing or stressing the speech.
:::	Colon(s)	Indicates prolongation of an utterance.
(hhh)		Audible exhalation
? or (.hhh)	High Dot	Audible inhalation

| (text) | Parentheses | Speech which is unclear or in doubt in the transcript. |
| ((italic text)) | Double Parentheses | Annotation of non-verbal activity. |

Jeffersonian Transcription Notation is described in G. Jefferson, "Transcription Notation," in J. Atkinson and J. Heritage (eds), *Structures of Social Interaction*, New York: Cambridge University Press, 1984.