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The experiences of adults with intellectual disability and dysphagia

an exploratory study

Kasch, Rachael J

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The Experiences of Adults with Intellectual Disability and Dysphagia: An Exploratory Study

By

Rachael J Kasch

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Certificate of Ethical Approval

Applicant:

Rachael Kasch

Project Title:

What are the experiences of adults with Intellectual Disability and Dysphagia? An exploratory study.

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ABSTRACT

Background: Very little is known about the experiences of adults with Intellectual Disability (ID) and dysphagia. Research completed with other population groups suggests dysphagia can lead to depression and social isolation. Speech and Language Therapy (SLT) dysphagia management guidance currently focuses predominantly on reducing the physical risks associated with dysphagia.

Aims and Objectives: The overall aim of the study is to explore the physical, social and psychological experiences of adults with ID living with dysphagia. The three objectives of the study are to develop recommendations for services working with adults with ID and dysphagia, provide a platform for a marginalised group to voice their opinions on a topic which is absent in the literature and to promote inclusive research with adults with ID.

Method: A qualitative method underpinned by an interpretivist paradigm was adopted. Adults with ID were involved in the design of the study. Twelve semi-structured interviews were completed with participants with ID and dysphagia. Interviews were transcribed and analysed using thematic analysis.

Results: People with ID can be meaningfully involved in qualitative research. Thematic analysis generated four main themes; Psychological responses to food and drink, Independence, Physical health consequences of dysphagia and SLT services. Findings indicate that along with the known physical health risks, dysphagia can also have a significant psychological and social impact on adults with ID.

Conclusions: Recommendations are made for service improvements to dysphagia services. The findings indicate services should provide equal consideration of the physical, social and psychological impact of dysphagia as standard practice.

CONTENTS

CHAPTER 1.0: INTRODUCTION

Intellectual Disability (ID) affects 2-3% of the population worldwide (Department of Health (DoH) 2001). Dysphagia is recognised as one of the five key areas of risk for people with ID (National Patient Safety Agency 2004). Impaired quality of life, malnutrition, dehydration, aspiration, choking and even death can all result from having dysphagia (The Royal College of Speech and Language Therapists (RCSLT) 2009). The Mencap report 'Death by Indifference' (2007) clearly illustrates the significance of dysphagia for adults with ID in which dysphagia was a contributing factor to all deaths in the report.

The prevalence of dysphagia in people with ID is reported to vary between 8% and 49% (Robertson et al. 2017). Despite such prevalence of dysphagia in this population, adults with ID have yet to be asked about their experience of living with dysphagia. As a Speech and Language Therapist (SLT) working with adults with ID and dysphagia, patients have often expressed their dislike and embarrassment of having to eat adapted food and liquids such as pureed textures and thickened fluids. Such thoughts and feelings on this particular topic however, have not been researched at all from the service users' perspectives. This exploratory study will take the first step in uncovering the neglected views and opinions of this client group by providing adults with ID the opportunity to give testimony to their experiences of having dysphagia.

1.1 Dysphagia

Although there are numerous definitions of Dysphagia, the one chosen for the purpose of this study is as follows:

> *'Difficulty in swallowing or impairment in the movement of swallowed*
>
> *material from the pharynx to the stomach'* (Logemann 1998: 9).

Researchers are paying increasing attention to the nature and experience of dysphagia (Roden and Altman 2013, Sheppard et al. 2014). There is however a dearth of research concerning the experience of having dysphagia from the perspectives of adults with ID. Other patient groups such as those with head and neck cancer have been given the opportunity to speak out about living with dysphagia (Martino, Beaton and Diamant 2009, Paris et al. 2013, Nund et al. 2014). Such research found dysphagia significantly reduced quality of life and whilst SLT focusses on the physical properties of dysphagia, the social and emotional consequences are neglected. Rather than also examining the perspectives of adults with ID about dysphagia, the literature

with this client group focuses predominantly on carer skill and knowledge (Chadwick, Joliffe and Goldbart 2002, Crawford, Leslie and Drinnan 2007, Tredinnick and Cocks 2013, Chadwick et al. 2014). The voices of adults with ID remain absent in the literature.

1.2 Intellectual Disability

The term intellectual disability is a highly contested one and not easily defined. The ICD-10 Classification of Mental and Behavioural Disorders (World Health Organisation (WHO)) defines ID as:

> *'… a condition of arrested or incomplete development of the mind,*
>
> *which is especially characterised by impairment of skills manifested*
>
> *during the developmental period, which contribute to the overall level*
>
> *of intelligence, i.e. cognitive, language, motor and social abilities. …*
>
> *Adaptive behaviour is always impaired …'* (1992: 33)

A differing definition of ID is offered by the DSM-V Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 2013):

> *'(a) Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.*
>
> *(b) Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without on-going support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work and recreation.*
>
> *(c) Onset of intellectual and adaptive deficits during the developmental period.'*
>
> (2013: 33)

Interestingly, the majority of ID definitions appear very clinical and reflect the medical model of disability which places the focus on the disabled person's impairment as a 'problem' that needs fixing. The Intellectual Disability Rights Service (IDRS) however offers a sociological definition of ID; one which fits more comfortably with my values as a researcher. They define

ID in regards to the support needs of the individual, stating that the effect of someone's disability is something that can vary and be increased or decreased by external factors (IDRS 2009). This definition very much reflects the social model of disability in which the problem of disability resides in society which requires restructuring to facilitate the inclusion of this client group (Oliver 1990). The distinction between the social and medical model will be discussed further in the following section.

People with ID are a vulnerable and disadvantaged population (O'Hara 2008). There are approximately 1.5 million people in the UK with an ID (Emerson et al. 2011) and due to increased survival rates for young adults with complex disabilities and reduced mortality amongst older adults with ID, epidemiological studies indicate a 7-8% population increase by 2020 (Emerson and Hatton 2008). This study provides this increasing population with the opportunity for their voice to be heard on an array of topics; in this instance, the chance to tell the researcher and others about their experience of living with dysphagia for the very first time.

1.3 Purpose of Study

Aim:

- *To explore the physical, social and psychological experiences of adults with Intellectual Disability living with dysphagia.*

Objectives:

- *To develop recommendations for services working with adults with Intellectual Disability and dysphagia.*

- *To provide a platform for a marginalised group of people to voice their opinions on a topic which is absent from the literature.*

- *To promote inclusive research with adults with intellectual disability.*

Research question:

- *What are the experiences of adults with Intellectual Disability living with dysphagia?*

The objectives of this research reflect my personal values, research interests and expertise. I believe adults with ID have a right to be heard and listened to and this study will provide

people with ID the much needed platform to express their opinions about having dysphagia and formulate the first contribution to research in this area.

1.4 Structure

The following part of this thesis will provide a literature review regarding disability research, the historical context for disability, involving adults with ID in research, existing literature studying the experiences of other client groups with dysphagia and finally existing research into dysphagia and adults with ID. Once the context for the study has been established, the researcher will then go on to describe the chosen design and methodology. An analysis of the results follows with detailed discussion of the findings and clinical implications. Finally, limitations and suggestions for future research will be considered.

CHAPTER 2.0: LITERATURE REVIEW

Three separate literature searches were conducted with support from an NHS librarian to carry the literature review. Details regarding search terms, databases and inclusion / exclusion criteria are presented in appendix 1.

2.1 Disability Research

Prior to the 1990s, people with disabilities were not included in research (Barnes 2008). Instead, disability research was comprised predominantly of either large-scale surveys or small-scale academic research into chronic illness (Barnes 2008). Oliver (2002) claims that research has historically failed disabled people on a number of counts. Most pertinent to this study he states 'it has failed to accurately capture and reflect the experience of disability from the perspectives of disabled people themselves' (Oliver 2002: 2). This argument is supported by Barnes and Sheldon (2007) who describe research as being an alienating experience for disabled research participants and something that is done to them over which they have little or no control.

The social model of disability often referred to as the big idea of the British disability movement (Hasler 1993) was introduced by Mike Oliver in 1983; a leading scholar in this area, to directly challenge the medical model of disability. The social model presents society as the main contributory factor in 'disabling' people and believes that barriers that restrict life choices for disabled people must be removed (Oliver 1983). This shift away from the medical model of disability was accompanied by a change in the way disability research was carried out (Barnes and Sheldon 2007); the promotion of the 'emancipatory' research paradigm exerted a dominant influence in the disability literature (Mercer 2004). The emancipatory research concept, first introduced by Mike Oliver in 1992, aimed to make disability research more relevant to the lives of disabled people (Oliver 1992) and improve their situations. Consequently, rather than research being carried out *on* people with disabilities, it was instead completed *with* them (National Disability Authority 2002).

The status of individual experience within emancipatory disability research however remains largely disputed. Barnes and Sheldon state 'on the one hand, it is argued that disabled people are the experts on their own situations and should have their long-silenced voices heard. On the other, it is argued that disabled individuals should not be the subjects of research - rather it is the disabling society that should be examined' (2007: 11-12). Despite this conflict, there has been an increasing body of literature exploring more inclusive and participatory ways to

involve adults with ID in research, the findings of which have been used to inform the methodology for this study. Before discussing the involvement of adults with ID in research however, a brief historical view of this specific client group will be considered.

2.2 Historical view of Intellectual Disability

Over the last 100 years, perceptions and attitudes towards people with ID have changed dramatically. Historically, adults with ID were labelled as 'imbeciles', 'feeble-minded' and 'morally defective' and the segregation of disabled people from the rest of society was common practice (DoH 1913: 136). Developments in research and clinical practice however led to a shift in attitude. The publication of Mental Deficiency: The Changing Outlook (Clarke and Clarke 1958) challenged the assumptions about the capacity of people with ID to learn new skills. These emerging positive attitudes of people with disabilities were further reaffirmed by the Chronically Sick and Disabled Person Act (Department of Health and Social Service (DHSS) 1970) which recognised and gave rights to people with disabilities. This was closely followed by a desire to move away from institutional settings (DoH 1971) and towards community care (DoH 1989). As a result, long-stay institutions for people with ID started to close and adults with ID began living in community settings.

Today, principles such as empowerment, independence, and maximisation of social inclusion feature throughout current policies that govern services for people with ID (DoH 2001, 2005, 2009, WHO 2010). Despite the existence of such documents, there are unfortunately still many instances of people with ID being treated unethically. The papers Transforming Care: A national response to Winterbourne View Hospital (DoH 2012) and Death by Indifference (Mencap 2007, DoH 2013) convey this injustice pertinently. Nonetheless, the shift towards more inclusive approaches within disability research coupled with the promotion of rights and independence for adults with ID, has resulted in an expanding body of literature involving this client group. A summary related to the ways in which adults with ID have been involved in research will now be discussed.

2.3 Involving adults with Intellectual Disability in Research

As previously mentioned, people with ID have historically been excluded from research (Mactavish, Mahon and Marie 2000). They tended to be the subject of research rather than active participants (Gates and Waight 2007). More recently however, there is a growing number of studies examining inclusive methodologies and advocating meaningful involvement

of adults with ID in research (Jephson 2015, Kidney & McDonald 2014, McDonald, Kidney and Patka 2012).

Some examples of research designs used with adults with ID will now be briefly discussed. Kidney & Mcdonald (2014) employed two adults with ID as research advisors. The advisors helped design every aspect of the implementation of their research. Similarly McDonald, Kidney and Patka (2012) hired advisors with ID to ensure all the research strategies and materials used were appropriate. A more participatory approach was used by Bollard (2010) and Cook and Inglis (2012). Bollard (2010) utilised a steering group consisting of adults with ID to help oversee the research and develop a questionnaire tool. Cook and Inglis (2012) worked more collaboratively with a group of men with ID to uncover how people with ID make informed choices in relation to participation in research. The group of men were involved not only in the development of processes for data generation, but also the analysis of that data.

The complexities of involving adults with ID in research is a growing area of inquiry (Cook and Inglis 2012) and may go towards explaining the limited research completed with adults with ID on the topic of having dysphagia. Gaining consent is a challenging area which has been investigated by a number of researchers (Iacono 2006, Boxhall 2010, Iacono and Carling-Jenkins 2012, Lloyd 2013). Lennox et al. (2005) declare that although the Mental Capacity Act works as a safeguard to protect adults with ID, the complexities of the act can also deny them the right to be included in research. Jephson (2015) however argues that if applied correctly, the Mental Capacity Act guidelines provide a useful framework to support adults with ID to participate in research. Furthermore, it is estimated that between 50% and 90% of adults with ID have communication difficulties (BILD 2002). Complications of involving people with communication difficulties in research may also have contributed to the limited research body (Nind 2008). This explanation however locates the 'problem' with the individual who has been potentially excluded as a direct result of their difficulties, rather than due to a failure of others to adapt their communication style.

Adults with ID value participating in research (McDonald, Kidney and Patka 2012). Despite this being known, there is still only a relatively small body of literature investigating the views and perspectives of this client group. In comparison, the following section highlights the more comprehensive amount of research which has been completed with non-intellectually disabled adults investigating their perspectives of having dysphagia.

2.4 Existing research into experiences of other client groups having dysphagia

The body of literature describing the experiences of individuals without ID and with dysphagia is more comprehensive than that of adults with ID. Adults with Amyotrophic Lateral Sclerosis (ALS), Parkinson's disease and head and neck cancer (HNC) have all been given the opportunity to share their experiences of living with dysphagia.

The work of Martino, Beaton and Diamant (2009) is only one example of the numerous studies which examine the perspectives of non-learning disabled clients who have dysphagia. This study is of particular significance as its findings directly reflect practice generated evidence collated from SLTs working with adults with ID. The perspectives of clinicians, carers and non-learning-disabled patients regarding the consequences of having dysphagia were collected via focus groups. Grounded theory was then applied to generate a measure for these consequences. The study found that although clinicians, caregivers and patients all referred to pulmonary, nutritional and psychological consequences of dysphagia, their prioritisation of these topics varied. Whilst all patients prioritised the psychological consequences of dysphagia over the medical consequences, clinicians and carers ranked pulmonary and nutritional consequences as the most pressing.

Despite these findings supporting practice generated evidence collated from adults with ID, the limitations of this research do need to be considered. The choice of participants may have biased the results of this study. All carers involved in this study were those of patients with medical instability. It is somewhat unsurprising therefore to learn that the medical consequences of dysphagia were the more urgent issues for such caregivers. Alternative findings may have been obtained if caregivers of medically stable patients had been selected to participate. Although this study provides some insight into patient perspectives of dysphagia, the findings cannot be generalised to adults with ID, as those who were 'not cognitively able to participate in a group discussion' were excluded (Martino, Beaton and Diamant 2009: 519). It is therefore evident that there is a gap in the literature regarding the perspectives of adults with ID and dysphagia; a gap which this study aims to address.

The perspectives of other patient groups regarding the impact of dysphagia on quality of life have also been investigated. Paris et al. (2013) analysed questionnaires completed following a swallowing assessment of 30 patients with ALS. Those with dysphagia reported reduced quality of life particularly in regards to social health, in comparison to the non-dysphagic patients with the same condition. A number of patients however were helped to complete their

questionnaire by a nurse. This may have influenced answers provided by participants and thus skewed the results of this study. Nevertheless, the findings of this study are in agreement with an earlier study carried out by Plowman-Prine et al. (2009) who observed that depression and social isolation were reported as being more common when dysphagia is present. These studies offer insight into the potential impact of dysphagia on quality of life and reinforce the need to explore the effect of having dysphagia on the lives of adults with ID.

Another client group given the opportunity to share their perspectives of living with dysphagia are adults with Head and Neck Cancer (HNC). The experiences of people with self-reported dysphagia following non-surgical HNC treatment were explored via semi-structured interviews (Nund et al. 2014). Five interrelating themes emerged from a thematic analysis and recommendations were formulated based on these themes. As a result, the researchers advised services to address not only the physical but also the emotional and psychosocial changes impacting people with dysphagia. These psychological changes are also recorded in the more recent study with adults with HNC by Tian et al. (2017) who found a clear association between having dysphagia and scoring high in regards to fear and mental health. They concluded with the suggestion of using strategies to aid mental adjustment to cope with dysphagia and improve quality of life. This research further supports the perception that the psychological consequences of dysphagia are not always prioritised by clinicians. The prioritisation and experience of physical, social and psychological issues relating to dysphagia for adults with ID is yet to be explored.

The use of thickened fluids is an intervention frequently recommended for people with dysphagia (Steele et al. 2015, Chichero 2013). The dislike and failure to comply with such fluid modification recommendations are well documented (Finestone et al. 2001. Murray et al. 2014. Shim, Oh & Han 2013, Leiter & Windsor 1996, Rosenvinge & Starke 2005). A study completed by Lim et al. (2016) highlights the marked aversion to the long-term use of modified fluids, an area which has not been investigated with adults with ID. Thickened fluids were provided to people without dysphagia who were requested to trade quality of life for life-years via interviews. On average, respondents were willing to sacrifice 4 years of a 10-year lifespan not to be restricted to modified fluids.

The following section will illustrate the limited attention paid to the perspectives of adults with ID about the specific topic of having dysphagia.

2.5 Existing research into adults with intellectual disability and dysphagia

Research completed with adults with ID on the subject of dysphagia is minimal, focusing predominantly on carer skill and knowledge rather than individual experiences (Chadwick, Joliffe and Goldbart 2002, Crawford, Leslie and Drinnan 2007, Tredinnick and Cocks 2013, Chadwick et al. 2014). No research has yet been completed which voices the perspectives of adults with ID about living with dysphagia.

Training support staff is a fundamental role for SLTs working with adults with ID (RCSLT 2009). This may explain why literature regarding adults with ID and dysphagia is heavily weighted towards the effectiveness of dysphagia training for carers (Chadwick et al. 2014, Tredinnik and Cocks 2014, Crawford, Leslie and Drinnan 2007, Chadwick, Jolliffe and Goldbart 2002). Tredinnik and Cocks (2014) investigated the effectiveness of a one day dysphagia training course for carers of adults with ID. Those who received the training exhibited a significant increase in knowledge post training, both immediately and one month later. The results of this study reinforce the value of training for those who support adults with ID and dysphagia. However these results should be interpreted with caution. There is no evidence that the increased knowledge observed in the carers was then applied in practice. Carer knowledge does not necessarily reflect carer practice (Jenkins et al. 1998). Furthermore, carer knowledge was investigated only one month post-training. There is no evidence regarding the retention of this knowledge.

The retention of carer knowledge was addressed by Chadwick et al. (2014) who researched the effectiveness of training up to 10 months later. Their training focused specifically on modification of fluid consistencies and the use of thickness indicator model (TIM) tubes in training. The researchers concluded that the accuracy of drink texture modification was increased by the use of TIM tubes in training. On closer inspection however, fluid modification accuracy was only statistically significant when compared with the group who received no training whatsoever. There was no statistical significance when compared with the group who received training without TIM tubes. Furthermore, participants were requested not to practise thickening fluids during the length of the study. This is not an accurate reflection of reality where carers provide mealtime support on a day-to-day basis (Ball et al. 2011) and therefore have regular opportunity to thicken fluids. Additionally, the training sessions in this study were delivered by one of five trainers from a variety of professional backgrounds. Training styles can vary greatly and result in very different learning outcomes for recipients (Grohmann, Beller and Kauffeld 2014, Towler and Dipboye 2001). The researchers did not appear to consider the

potential impact of variation in trainer skill and style on the results of this study. A vital shortcoming of the study is the absence of patient involvement. Individuals were not asked their opinion of the TIM tubes. The researchers did briefly allude to patient involvement when querying if patient ownership of TIM tubes could potentially increase control over their own care. This however was not investigated further.

Lack of patient involvement is a theme which features throughout the literature relating to adults with ID and dysphagia. In the article 'Management of Dysphagia', the authors recommended that 'distractions such as loud radio or television should be removed [during mealtimes] to promote social interaction [and] people should be included with their peers at mealtimes as much as possible' (Dalton, Caples and Marsh 2011: 37). There is no consideration given to the preferences of adults with ID. Without asking adults with ID directly, these preferences will remain unknown. Smith, Teo and Simpson (2013) made equally presumptuous statements in their study which video records adults with Down syndrome eating independently. Based on their observations, the researchers suggested management strategies to promote safety and quality of life for patients. Conversely, their interpretation of quality of life was not defined and participants were not consulted about their proposed 'behavioural management' techniques which include the provision of and encouragement to use 'appropriate' eating utensils (Smith, Teo and Simpson 2013: 56). At no point did the authors explore the participants' perspectives regarding such interventions.

The health risks posed by dysphagia for adults with ID were researched by Chadwick and Jolliffe (2009) who carried out a descriptive investigation of dysphagia in adults with ID. Information about 99 adults with ID were analysed and the characteristics associated with dysphagia examined. Asphyxia, dehydration and poor nutritional status were considered the highest risks of having dysphagia. The study however focused only on the physical consequences of having dysphagia and failed to consider the potential social and psychological effects. Four years later, Howesman (2013) advocated the involvement of adults with ID and their carers in care planning around dysphagia. Despite these recommendations being made, evidence in this area is still lacking and no research has yet been carried out that draws on first-hand accounts of the ID population about their experiences of having dysphagia. Their perspectives about living with dysphagia remain unknown.

2.6 Conclusion

Increasing amounts of research are being carried out *with* adults with ID and literature advocating inclusive methodologies with this client group is continuing to expand. Researchers are finding new and empirical ways to meaningfully involve people with ID in research. Valuable information regarding the perspectives of those living with dysphagia can be collected using qualitative approaches. Recommendations can then be generated to improve future services for people with dysphagia. The significant gap in the literature regarding the perspectives of adults with ID living with dysphagia can no longer be ignored. This study is centred on the service users themselves. Listening to and understanding their unique individual experiences will not only provide valuable new knowledge that draws on real world experience, but also identify service improvement needs for those working with adults with ID and dysphagia.

CHAPTER 3.0: METHODOLOGY AND METHOD

    3.1 **Research Design**

The research design adopted in this study is primarily influenced by the interpretivist paradigm. Interpretivism is often linked to Max Weber (1864-1920) who suggested that in the human sciences we are concerned with Verstehen (understanding) in comparison to Erklaren (explaining); process rather than `facts' (Brooke 2013). This view is supported by that of Crotty (1998) who believes that knowledge and meaningful reality are constructed in and out of interaction between humans and their world and are developed and transmitted in a social context. As the interpretive approach focuses on understanding a phenomenon from individuals perspectives (Creswell 2009), a qualitative methodology has been selected for this study. By using a qualitative methodology, the depth, richness and complexity of peoples' experiences can be uncovered (Offredy and Vickers 2010); in the case of this research, the experiences of adults with ID living with dysphagia.

Qualitative research has been described as 'a situated activity that locates the observer in the world' (Creswell 2013: 43). Such qualitative research methods have become increasingly popular in healthcare research in recent years (Brookes 2007, Meyer 2000). Qualitative health research focuses on how social processes and practices in health care are created and what meaning they have for people within specific contexts (Lempp and Kingsley 2007). The qualitative approach is consistent with the aim and objectives of this study which are centred on exploring the experiences of adults with ID.

Qualitative research within an interpretivist paradigm can be undertaken through several different methodologies, the most commonly used including ethnography, grounded theory and phenomenology (Sutton and Austin 2015). Following consideration of a variety of qualitative methodologies, a phenomological approach was selected for this study. The main goal of phenomenology; to gain insights that inform practice strategies and enhance practitioners' understanding of and sensitivity to those they serve (Bourgeault, Dingwall and De Vries 2013), marries well with the aim and objectives of the research.

Figure 1 below illustrates the philosophical stance chosen by the researcher which underpins this study;
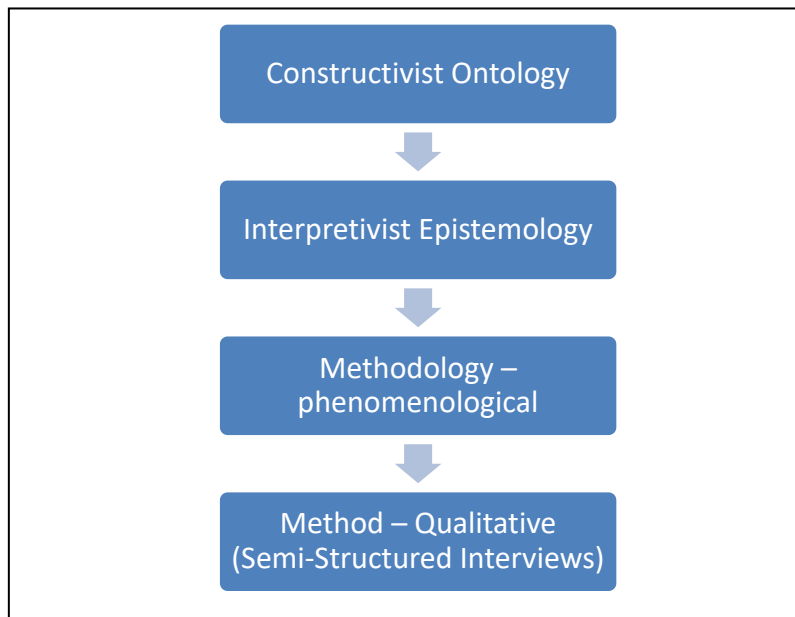
Figure 1: An overview of the philosophical stance chosen by the researcher.

A number of scholars have influenced the development of phenomenology, crucially those of Husserl, Heidegger, Merleau-Ponty and subsequently Sartre (Smith, Flowers and Larkin 2009). According to Husserl, phenomenology involves the careful examination of human experience and involves 'stepping outside of our everyday experience, our natural attitude as he called it, in order to be able to examine that everyday experience' (Smith, Flowers and Larkin 2009: 12). Heidegger's stance however is grounded in the lived world, 'the world of things, people, relationships and language' (Smith, Flowers and Larkin 2009: 16) and is concerned with the practical activities and relationships which we are caught up in and through which the world appears to us and is made meaningful (Smith, Flowers and Larkin 2009: 17). In comparison, Merleau-Ponty suggests that our sense of self is holistic and engaged in looking at the world rather than being subsumed in it, therefore we see ourselves as different from everything else in the world (Smith, Flowers and Larkin 2009: 18). Whereas Sartre believes 'existence comes before essence' (1948:26) and stresses the developmental, processual aspect of human being indicating that rather than the self being a pre-existing unity, we are instead always becoming ourselves (Smith, Flowers and Larkin 2009: 19).

The aim of this study is to focus on uncovering the experiences of adults with ID and learning about their 'lived world' in regards to having dysphagia. The researcher believes Heidegger's phenomenological approach provides the most appropriate grounding to provide a more

nuanced understanding of how adults with intellectual disabilities experience dysphagia on a day to day basis.

3.2 Data Collection

A role of the researcher in qualitative research is to access the thoughts and feelings of participants (Sutton and Austin 2015). Some methods of collecting qualitative data are reported to be more suited to phenomenology than others; these include in-depth interviews and the analysis of diaries and protocols (Finlay 2011). To access the thoughts and feelings of adults with ID about their experiences of having dysphagia, one-to-one semi-structured interviews were selected as the data collection tool in this phenomenological study.

People with ID have been successfully included in research via a variety of qualitative data collection methods including focus groups (Gibbs, Brown and Muir 2008, Llewellyn and Northway 2008) and one to one interviews (Hollomotz 2017, Mattila 2016). The risk of individual participants dominating conversations in focus groups however is well documented (Offredy and Vickers 2010). Coupled with the potential of high levels of acquiescence in the ID population (Rapley and Antaki 1996), focus groups were ruled out as the main data collection tool for this study. One-to-one interviews offer the researcher flexibility to cater for the communication needs of each individual and ensure participants' voices are heard; voices which may otherwise be lost in a group setting.

Questionnaires were discounted as the main data collection tool as they not only provide superficial responses, they also rely heavily on literacy skills and / or rater ability (Bowling 2014); skills which the ID population may be lacking. Interviews were chosen over questionnaires so as to allow the researcher to generate thick description (Geertz 1973 cited in Bryman 2008).

Despite interviews being time consuming and dependent on the skill of the interviewer (Bowling 2014), they allow researchers to collect information and expand knowledge about individuals' thoughts and feelings (Offredy and Vickers 2010); key objectives of this study. Due to the prevalence of communication difficulties in the ID population (BILD 2002), it is advantageous if interview topics can be used flexibly and interview schedules adapted to obtain meaningful participant involvement. Semi-structured interviews provide the interviewer with such desired flexibility. On this basis, structured interviews in which respondents receive exactly the same interview stimulus as each other (Bryman 2008) were

disregarded. Similarly, as participants with communication difficulties are likely to require prompting to stay on topic, unstructured interviews were also ruled out.

As recommended by Kidney and McDonald (2014), one to one semi-structured interviews took place at a local location chosen by each participant to assist them in feeling as comfortable as possible. Based on the research design of Jephson (2015) familiarisation sessions were offered prior to interviews to build rapport between interviewer and participant and provide the interviewer opportunity to adjust to each individual's communication style. Interviews were audio recorded and later transcribed using guidance provided by Sutton and Austin (2015);

> - All audio recordings should be transcribed verbatim, regardless of how intelligible the transcript may be when it is read back.
> - Lines of text should be numbered.
> - Once the transcription is complete, the researcher should read it whilst listening to the recording and do the following;
>   - Correct any spelling or other errors
>   - Anonymise the transcript so that the participant cannot be identified from anything that is said (e.g. names, places, significant events)
>   - Insert notations for pauses, laughter
>   - Include any other contextual information that may have affected the participant (e.g. temperature or comfort of room)

Figure 2: transcription guidance based on Sutton and Austin (2015)

As qualitative data analysis is an iterative and a reflexive process, field notes were documented during each interview (Stake 1995). With participant consent, interviews were audio recorded using an encrypted voice recorder. Regular breaks were offered to participants when required. No maximum time was allotted to the completion of an interview. Literature emphasises the value of using visual resources in assisting data collection with adults with ID (Gates and Waight 2007). Consequently, photo elicitation, 'based on the simple idea of inserting a photograph into a research interview' (Harper 2002: 13) was used in the design of this study to support data collection. Prior to interviews, participants were asked to take photographs that represented living with dysphagia. These photographs were then used to facilitate discussion with that individual during their interview. Harper (2002: 13) claims that using photo elicitation in an interview not only elicits more information, but also 'evokes a different kind of information'. Interviews were based on the following broad topics:

(i)   General information about eating and drinking
(ii)   Food textures
(iii)   Drink textures
(iv)   SLT input
(v)   Photo elicitation

The interview topics were designed around previous research findings (Nund et al. 2014, Paris et al. 2013, Martino, Beaton and Diamant 2009). As discussed earlier, much of the literature researching the experiences of dysphagia found that patients referred to not only the physical consequences of dysphagia but also the social and emotional consequences. Questions that stimulated participants to talk about their feelings in relation to having dysphagia were purposefully included to encourage information to be shared on these topics. A blank interview schedule can be found in appendix 2.

3.3 People and Patient Involvement

INVOLVE, an organisation funded by the National Institute for Health Research to support active public involvement in the National Health Service (NHS), advocates the involvement of the public in research. They define participatory research as projects which involve services or carers as partners in a research project (INVOLVE 2017), elements of which are embedded throughout the design of this study. As there are numerous challenges to achieving a truly participatory process with adults with ID (Gilbert 2004; McLaughlin 2010), service users were not involved in all aspects of the decision-making and conduct of this study. Participation can come in many forms and does not need to include all components of the research process (Conder et al. 2011). It remains more common for people with ID to be included in roles such as membership of advisory committees, analysis of data, advocating or supporting peers, and disseminating findings (Grant and Ramcharan 2009). This is reflected in the design of this study in which public involvement featured in the following areas; the production of participant information sheet, initial interest in taking part form, consent form, interview schedule, data analysis and distribution of research findings.

As recommended by Kidney and McDonald (2014) all easy read documents were produced in consultation with adults with ID. A local advocacy working group of adults with ID reviewed the study documentation and made positive changes to ensure they were accessible to adults with ID, for example the working group suggested changing from the use of Picture Communication Symbols (PCS) to Photosymbols as they felt Photosymbols were more accessible to the ID population. Additionally, in regards to participant certificates, the working group proposed a more mature presentation using only black and white ink with no pictures

rather than the original colourful 'more childlike' version they were sent to comment on. As reported earlier, patient involvement also featured in point five of data analysis; theme defining and naming as preliminary themes generated by the researcher were presented to the advocacy working group for feedback. Although the working group suggested using direct quotes as theme names, this unfortunately was not possible as the data did not hold any fully representative quotes. Dissemination of research findings also included patient involvement. The advocacy working group were consulted on writing the easy read leaflet containing the results of the study and have provided links in order to support dissemination of the research findings.

3.4 Participants

A purposive sample (Bowling 2014) of twelve adults with ID and dysphagia participated in this phenomenological study. Demographic information of participants is illustrated in Table 1 below:

SEX:	Male	4
	Female	8
AGE:	19-30	4
	31-45	3
	46-60	2
	60+	3
ETHNICITY:	White British	9
	Asian British	2
	Asian Other	1
LIVING ARRANGEMENTS:	Residential home	6
	Nursing home	1
	Family home	3
COMMUNICATION METHOD:	Verbal	9
	Voice Output Communication Aid	2
	Communication Book	1
DYSPHAGIA RECOMMENDATIONS:	Normal fluids	5
	Thickened fluids	7
	Soft cut up foods	6
	Soft mashed foods	3
	Soft Puree foods	3

Table 1: Demographic information of participants

Three quarters of the participants communicated verbally whereas 17% used a voice output communication aid (VOCA) and 8% a communication book; a book containing pages of symbols which are used to aid communication (Communication Matters 2017). In regards to individual dysphagia recommendations, 58% of participants were recommended to have thickened fluids whilst the remaining 42% drank normal thin fluids. Just over half of participants had been recommended to eat soft cut up foods, a quarter had their foods mashed and the remainder had their foods pureed.

Financial incentives were not offered to participants for ethical reasons; it may be viewed that participants are being coerced to provide positive feedback about their experiences of a service (Alderson and Morrow 2011). Instead, a certificate was issued to those who took part.

3.5 Recruitment

Participants were identified and recruited from the Learning Disability service of an English community healthcare NHS Trust via a Dysphagia and Nutritional Support (DANS) clinical reference group (CRG). The DANS CRG consists of a variety of registered health professionals including SLT's, dieticians, physiotherapists, nurses, pharmacists and dentists. The community healthcare trust, which will remain anonymous to protect participant identities, encompasses a mixed catchment area of varying socio-economic demographics. A presentation was provided to the trust DANS CRG regarding recruitment to this study (appendix 5). Clinicians from the DANS CRG made direct contact with those who met the inclusion criteria. The following participant inclusion and exclusion criteria were used for this study;

Inclusion Criteria

Participants must:

- Have a diagnosis of ID and dysphagia
- Have the mental capacity to consent to participate in the study (as per the Mental Capacity Act 2005)
- Have received a community dysphagia service from the local community Healthcare Trust between 2007 and 2017.
- Have been 19 years of age or over when they received the dysphagia service.

Exclusion Criteria

Participants must not:

- have received a community dysphagia service directly from the researcher.
- lack the mental capacity to consent to participate in the study (as per the Mental Capacity Act 2005)

Table 2: Participant inclusion and exclusion criteria for the study.

The DANS CRG member discussed the easy read participant information sheet with each potential participant (appendix 6). If the potential participant was interested in taking part in the study, they were then asked to complete the 'interested in taking part in the study' form (appendix 7). Completion of this form provided the researcher with consent to access participant data in order to contact them about the study. The researcher made contact with each participant at least one week after they had completed the initial interest form. This approach was based on the recommendation of Cook and Inglis (2011) who found that giving

time for participants to assimilate the information made for an effective recruitment strategy in their investigation of how people with ID make informed choices in relation to participating in research. The researcher chose to contact the participant directly, rather than via their significant other, as modelled in the research design of Nicholson, Colyer and Cooper (2013). Each participant was asked to complete a consent form (appendix 8) and verbal consent was also acquired prior to each interview. Although the number of participants included in the study was not pre-determined, a target of five participants had been set. A total number of twelve participants took part in the study.

3.6 Data Analysis

Each interview was transcribed verbatim into Microsoft Word by the researcher whilst simultaneously making notes. Despite being a time-consuming process, it provided the researcher with the opportunity to become familiar with the data in preparation for data analysis as per Webb's 'Osmosis method' (Webb 1999: 329). Photographs taken by participants acted as discussion points during interviews. The photographs that were taken by participants however did not add any new data as topics had already been previously discussed during interviews. Photographs consisted mainly of foods participants were no longer able to eat.

Transcriptions were then analysed using thematic analysis; 'a method for identifying, analysing and reporting patterns within data' (Braun and Clarke 2006: 79). Thematic analysis was the chosen data analysis method due to it being a flexible and useful research tool which provides a rich and detailed, yet complex, account of data (Braun and Clarke 2006). The thematic analysis followed is illustrated in Table 3 below as described by Braun and Clarke (2006);

Table 3 - Phases of thematic analysis (Braun and Clarke 2006: 35)

The thematic analysis of data was an iterative process and main themes were only finally defined after multiple reviews. The themes were chosen due to their reoccurrence across participant's accounts and relevance to research questions. An example of the data analysis process undertaken can be found in appendix 3 along with the application of thematic analysis to an extract of interview data. Anonymised preliminary themes were sent to the researcher's

supervisory team as recommended by Pope, Ziebland and Mays (2000) to support the reliability of data analysis. Preliminary themes were also presented to the advocacy working group for feedback. More detailed information regarding the number of participants identifying each theme and sub-theme is presented in appendix 4.

3.7 Ethical Considerations

An application for ethical approval was successfully obtained from the Coventry University ethics committee. Due to the involvement of vulnerable adults in the study, an Integrated Research Application System (IRAS) application was also required and granted. Approval was also sought and awarded by the local trust research and innovation team (appendix 9). As per the work of Beauchamp and Childress (2001), reasonable efforts were made in the design of this research to avoid foreseeable risks or harm to participants, a summary of which is provided in Table 4 below. As a health professional, the HCPC code of practice informed my position as a researcher. Thorough consideration of the ethical issues and strategies to overcome these resulted in IRAS ethical approval being granted along with HRA approval (appendix 10). In addition to written consent, verbal consent was gained from each participant prior to interview.

> o   Should a participant disclose that they have been treated badly or are at risk, the researcher will need to breach confidentiality and report the information to the relevant bodies (e.g. safeguarding vulnerable adult team). This was made clear on the participant information sheet and again reiterated at the start of the interview, so it did not come as a surprise to participants.
>
> o   Should a participant become distressed during an interview, they have the option to terminate or reschedule the interview. The participant information sheet lists the options available. During the interview, the researcher asked the participant on a number of occasions if they were happy to continue with the interview and if they would like a break. This took the burden off the participant to remember this option and articulate this request to the researcher.
>
> o   Only members of the participant's existing clinical care team will have access to their personal information to determine eligibility of patients. All clinicians abide by NHS confidentiality code of practice and also Trust policy's such as the confidentiality and data protection policy to ensure confidentiality is not breached. The sponsor will not have access to participant's personal data.
>
> o   Data was collected on an encrypted audio recorder. Any printed participant identifiable information including photographs were stored in a locked cabinet on Trust property, and typed/recorded data stored in a restricted access permissions folder, set up via IT on the Trust network, accessible only to the researcher and mentor. Non-identifiable data will be transported to the researcher's house on an encrypted memory stick and stored on a password protected computer, in a house with an alarm.

Table 4 – Ethical issues and strategies

3.8 Reflexivity

It is acknowledged within qualitative research that the prior assumptions and experiences of the researcher may threaten the validity and reliability of the research process (Golafshani 2003). An ongoing process of reflexivity regarding the researcher's subjective experiences forms an essential part of the research process (Collican 2004). A reflexive diary was kept by the researcher during the research process to limit the influence of the researcher's preconceptions on the research results (Savin-Baden and Howell 2013). As an SLT, a certain amount of professional assumptions based on clinical knowledge and experience are brought to the research process. Every effort was made however to remain open minded throughout the data collection and analysis process. A discussion of reflexivity will be elaborated on at the end of chapter five following the experience of data collection.

CHAPTER 4.0: FINDINGS

This section will present the main findings from the study. A thematic analysis based on Braun and Clarke (2006) generated four main themes. The four main themes are introduced and summarised below;

Theme 1 - Psychological responses to food and drink.

All twelve participants spoke about the psychological effects of having dysphagia. Interview data largely comprises narratives containing emotional accounts relating to eating and drinking modified textures. Although the majority of participants provide negative accounts of eating modified foods, attitudes towards thickened fluids are conflicting. Disparate views are also expressed in regards to the experience of eating out socially with dysphagia.

Theme 2 - Independence

Diverse opinions are provided on the topic of independence. Whilst a small number of participants welcome mealtime assistance, the vast majority provide negative accounts and express a preference for increased mealtime independence.

Theme 3 - Physical health consequences of dysphagia

The majority of participants refer to potential physical consequences of having dysphagia and demonstrate the weighing up of information in regards to risk and preference. This topic however features minimally in comparison to psychological responses to having dysphagia.

Theme 4 - Speech and Language Therapy Services

Participants provide feedback in regards to previously received SLT input and propose suggestions for improvement.

Each main theme encompasses a number of sub-themes, as displayed in Figure 3 below:

THEME 1:
PSYCHOLOGICAL
RESPONSES TO FOOD AND
DRINK

Subthemes:

- Prohibited foods

- Modified food textures

- Thickened Fluids

- Eating out socially

THEME 4: SPEECH &
LANGUAGE THERAPY
SERVICES

Subthemes:

- Emotional and
psychological response to
SLT input

- SLT Communication

-SLT future suggestions

INDIVIDUAL

THEME 2:
INDEPENDENCE

Subthemes:

- Being assisted

- Utensils

- Cutting up food

- Verbal prompts &
observation

THEME 3: PHYSICAL
HEALTH CONSEQUENCES
OF DYSPHAGIA

Subthemes:

- Choking

- Weighing up of
information

Figure 3: Visual representation of themes and subthemes generated from data.

Themes and corresponding sub-themes are discussed in detail below with supporting transcription excerpts. All interview information has been anonymised and pseudonyms have been used.

4.1 Theme 1: Psychological responses to food and drink

This section demonstrates the study findings in relation to individuals feelings towards food and drink. The four sub-themes of this section are as follows; *prohibited foods, modified food textures, thickened fluids* and *eating out socially.*

4.1.1 Sub theme: Prohibited foods

Despite variation amongst accounts, all twelve participants share the psychological impact of being prohibited from eating certain foods due to their dysphagia. The vast majority of participants provide a negative description of the imposed food limitations. The psychological impact of being prohibited from eating certain foods is apparent in Ali's narrative when describing what dysphagia means to him;

> *'Well certain things I can have and certain things I can't have, can't have kidney beans, [feel] awful about it'* (Ali, Male)

Similar feelings of sadness and unhappiness due to food restrictions are described by a number of participants. Tracey, who used to regularly enjoy a beef curry, explains how her diagnosis of dysphagia has affected her psychologically;

> *'can't have a beef curry, I miss that, it makes me sad'.*

Similarly, Peter, whose dysphagia diagnosis now prohibits him from eating salad, provides an emotive account of the last time he ate it;

> *'We went to London last year and I did have some salad. I like salad but I'm not*
>
> *allowed to have it now, make me sad' .*

Whilst Mary lists the foods she is no longer able to eat and expresses her subsequent unhappiness;

> *'can't have garlic bread, baguettes, salad stuff, lettuce, beetroot, makes me sad'.*

In addition to sadness, feelings of frustration and annoyance were also expressed towards enforced food restrictions. A sense of unfairness is described by participants in regards to other people being able to eat the foods they no longer can;

> *'can't have pasta and chocolate like other people, [feel] frustrated'* (Jasmin)
>
> *'it's frustrating cus they let the other man eat crisps but they won't let me eat them'*
> *(*Tracey*)*

No participants describe food restrictions positively. The abundance of negative reports indicates the detrimental psychological impact dysphagia may have on adults with ID.

4.1.2   Sub theme: Modified food textures

Individuals diagnosed with dysphagia are often recommended to eat modified food textures (NPSA 2011). Depending on the nature and complexity of dysphagia, a variety of food textures can be recommended; thin purée, thick purée, pre-mashed and soft moist (normal or cut up) (NPSA 2011). All participants involved in this study have been advised to eat one of the listed modified food textures.

Only one single participant, Paul, describes modified food textures positively. Using his VOCA, Paul expresses he feels '*happy*' about eating a soft moist diet. In stark comparison, the majority of participants provide very negative accounts of eating modified food textures.

> *'I have to have soggy blended bread eugh it tastes horrible eugh, told them I'm not*
>
> *eating that I don't like it' (Jack)*

> *'it's puree, I don't like it it's horrible, horrible. I wanna eat normal food' (Tracey)*

Some participants expressed feeling patronised and treated like a baby due to the modified food textures recommended. Ali describes;

> *'they think I'm a baby. I get so frustrated, I get really upset, when I get home it'll be*
>
> *all chopped up again, I don't want it'*

Similarly, an awareness of being different to others and longing to be 'normal' is evident in Chris's narrative;

> *'[mashed food] makes me upset, I don't want it anymore, wanna be normal like my*
> *friends, makes me sad'* (Chris, male)

No patterns emerged in relation to any particular food texture. Negative comments were shared from those who ate all four food textures.

4.1.3   Sub theme: Thickened Fluids

Thickened fluids are often used in the management of dysphagia (RCSLT 2009). Fluids can be thickened to various degrees depending on the type and complexity of an individual's

dysphagia; syrup, custard and pudding consistency (NPSA 2011). Participant feelings associated with drinking thickened fluids are extremely varied.

Just under half of participants communicate positively about having thickener in their drinks. Helena points to the symbol '*like it*' in her communication book when asked her opinion of thickened fluids. This view is reiterated by Peter who provides a very positive representation of thickened fluids;

> '*you know that Thick and Easy in your drink, I like it, tastes alright, love a cup of tea*'.

The remaining half of participants describes thickened fluids as undesirable and unfavourable;

> '*I don't like it, it's too thick, horrible, horrible, eugh, don't like it you can taste the*
>
> *powder*' (Jack)
>
> '*The hospital put me on three scoops of thickener, it's horrible*' (Tracey).

Jasmin poignantly describes how thickened fluids make her stand out from her non-disabled peers and the psychological affect this has on her;

> '*it's horrible, makes me angry, people watch me having it, the lads can see me*
>
> *have it, I wanna drink like normal people*'

Pam, who previously had thickened drinks but now drinks normal thin fluids, provides a comparison of the two;

> '*it's better without the powder, I like it without the powder*'.

4.1.4   Sub theme: Eating out socially

Social inclusion is an important goal for people with ID (Simplican et al. 2015). Adults with ID want to socialise, have friends and be part of their community (Wilson et al. 2016). This may explain why ten of the twelve participants eat out regularly. Feelings of embarrassment and discomfort however were expressed by just under half of participants in regards to eating modified diets in public. Ali describes the psychological impact of eating a modified diet in a restaurant;

> '*make me feel uncomfortable cus when other people are eating normal food but not*
>
> *me*'

Jasmin also refers to the uncomfortable awareness of being different from others when eating a modified diet in public with non-disabled peers;

> '*makes me upset, I wanna be normal like my friends, the lads can see me, I don't want it anymore*'

The detrimental psychological effects of eating a modified diet in public is undoubtedly visible in Chris's touching account of when he last ate out;

> '*we went for a meal right and erm I got so upset, crying, crying, I want to go home*'

Similar messages were conveyed by non-verbal participants. Using her communication book, Helena points to the symbol '*sad*' when asked how it feels eating puree foods in the pub. When asked to explain why she feels sad, she communicated '*people look*'.

4.2 Theme 2: Independence

Historically, people with ID have lacked authority and control over their lives (Bjornsdottir, Stefansdottir and Stefansdottir 2015). This may explain the unmistakable desire for independence which poignantly resonates throughout participant interviews. Findings in relation to independence will be shared under the following four sub theme headings; assistance, adapted eating and drinking utensils, cutting up food and verbal prompts and observation.

4.2.1 Sub theme: Assistance

Approximately a third of people with ID require assistance when eating (Ball et al. 2012). During interviews, I was struck by the psychological impact of receiving mealtime assistance on people with ID and dysphagia. A clear dissatisfaction with the assistance received was reported by half of the participants. With frustration, Jasmin recounts her inadequate experience of being assisted to eat;

> '*the staff are too slow in there [*pointing to dining room*]. They talk to each other! Feed me!*'

A sense of fear and vulnerability is communicated not only by Tracey's words but also through her expressive body language. Whilst shaking her head and frowning, Tracey states;

'they feed me too quick. It's horrible. I could choke!'

In contrast, the remaining half of participants provide positive reports in regards to their experience of being assisted to eat and drink. Anuja uses her VOCA to express she feels 'excited' about being assisted to eat whilst Ali shares 'yeah it's alright innit'.

4.2.2 Sub theme: Adapted Eating and drinking Utensils

The immense value and significance placed by participants on the use of adapted eating and drinking utensils took me by surprise. The gratitude and appreciation Jack expresses towards the provision of adapted utensils is powerfully illustrated by his choice of the term 'everything' in his interview. His satisfaction of the increased control and independence offered by his utensils is unmistakable;

> Interviewer: *'What do your utensils mean to you?'*

> Jack: *'Everything. Mean everything to me. I can eat properly, it stop my plate going on the floor, it don't fall. Without it I drop my food on the floor and on the table'.*

I was particularly taken aback by the significant value participants attributed specifically to the use of a straw when drinking. Ali couldn't emphasise enough just how valuable his straw is to him and his pleasure at the subsequent increased independence;

> *'I have a straw, it's really good. I can't drink out of a normal cup, I spill everything'.*

Very similarly, Peter also expresses his delight in the autonomy provided by the use of a straw;

> *'I use a straw so that I can do it myself, it's better than them doing it'.*

4.2.3 Sub theme: Cut up food

People with ID may be recommended to have their food cut up due to 'cramming'; pushing a large amount of food into their mouth when eating (Gesky 2007). To reduce the risk of choking, SLT may advise foods to be cut up into small pieces before being served. I was struck by the intensity of participant thoughts and opinions in relation to this topic, particularly the numerous powerful expressions of anger, mistrust and frustration. With a raised voice, Mary declares;

> *'Don't like staff cutting up my food, [makes me] angry cus it's in little bits, I like big*

> *bits'.*

Pam did not attempt to hide the sheer infuriation and irritation caused by staff doubting her skills and ability to cut up her own meal. With demonstrative hand gestures, Pam shouts;

> 'they cut it but I want to do it my way! I want to be independent! They don't trust me. I wish they did. Make me angry'

Similarly, Samia is almost brought to tears when telling me how disempowered and angry she feels when her food is cut up for her;

> 'Sometimes I get really upset about it. If I need some help I'd ask. Sometimes I just go to my bedroom and cry. It make me feel better'

Interestingly, with a big smile on her face, Samia then goes on to express just how satisfied and fulfilled she would feel if given the opportunity to cut up her own meal;

> 'it'd make me feel better in myself. Proud of myself.

A similar sense of powerlessness caused by the simple yet evidently unwelcome task of having food cut up by others is also clearly expressed by Peter. His irritation and annoyance at not being allowed in the kitchen particularly stood out to me when describing his situation;

> 'I can do it myself but my Keyworker does it. I don't like it. I'm not allowed to go in the kitchen no more but I want to do it myself. It's frustrating.'

Despite the majority of participants expressing unhappiness in regards to having their food cut up, one participant, Paul states it is 'nice' to have his food cut up. The remaining participant conveys neutral feelings about having his food cut up stating they 'don't mind' (Chris).

4.2.4 Sub theme: Verbal Prompts and observation

Rapid eating is a frequent problem among adults with ID and can pose a threat to health (Ercheverria and Miltenburger 2012). To reduce risks, the use of verbal prompts and observation at mealtimes are often recommended. Interestingly, conflicting opinions are expressed by the two participants who receive verbal prompts at mealtimes. Whilst Ali appears happy with the receipt of verbal prompting;

> 'they say slow down and take little bites. I don't mind them doing that'

Pam expresses great irritation regarding the very same management strategy. Whilst frowning, Pam furiously states;

'they say you eat too fast, makes me angry'.

Conflicting views are also provided by the two participants who receive observations at mealtimes. Ali provides a relaxed account of being observed to eat;

'I can eat one in a room with somebody so they can keep an eye on me, I don't mind

that'

Whereas in stark comparison, Chris's response illustrates a clear preference to be left alone when eating. Whilst shaking his head, Chris heatedly proclaims;

'it put me off. Move away!'

4.3 Theme 3: Physical health consequences of dysphagia

Malnutrition, dehydration, aspiration, choking and even death can result from having dysphagia (RCSLT 2009). During the interviews**,** 82% of participants refer to physical health consequences of dysphagia. This section has been split into the two sub themes; *Choking* and *weighing up of information*

4.3.1   *Sub theme: Choking*

The vast majority of participants refer to choking as a potential consequence of having dysphagia. The following quotes demonstrate the reality of the risks several participants confront each time they eat or drink. When asked why she eats a modified diet, Mary very factually responds;

'*cus I might choke, gets stuck*'.

Similarly, Samia explains '*I used to choke*' when asked why her fluids are thickened. The potential consequence of being admitted to hospital due to choking is referred to by a number of participants. When asked why they eat a modified diet, participants somewhat unemotionally explain;

'*cus I choke, end up in hospital*' (Ali)

'*you get choked, go to hospital*' (Chris).

Other participants introduce coughing and being sick as other possible consequences of having dysphagia;

Interviewer: *'What would happen if you ate normal food?'*

Helena: *[points to throat and coughs]*

Interviewer: *'What would happen if you ate normal food?'*

Pam: *'make you sick'*

Only one participant refers to aspiration as a potential consequence of their dysphagia. When being questioned about normal fluids Tracey states '*I'm not supposed to drink that, the doctor said, cus I'd aspirate*'.

4.3.2   Sub theme: Weighing up of information

Just over a third of participants demonstrate the weighing up of information relating to the risks they take when eating or drinking unmodified food and drink textures. The following narratives convey the internal conflict participants experience when balancing the wish to eat or drink normal textures with a desire to remain safe and healthy.

Although Jasmin states she would '*love to*' eat chocolate, she goes on to explain she chooses not to as '*chocolate might get stuck*'. Mary speaks similarly about eating chips whole rather than cut up. Although she dislikes having her food cut up, she states she would not like to eat her chips whole '*cus I might choke, gets stuck*'. Tracey reveals that although it would feel '*wonderful*' to eat biscuits, she chooses not to eat them; *'no I can't, it'd get stuck and I'd choke, I could die*'. Likewise, although Jack expresses he would prefer to drink normal fluids, he also states *'I like having thickened fluids. Normal fluids make me cough*'.

Findings suggest adults with ID and dysphagia have a basic understanding of the possible health consequences of dysphagia however express limited emotions in regards to these.

4.4   Theme 4: Speech and Language Therapy Services

SLT has a unique role for the assessment, diagnosis and management of dysphagia (RCSLT 2009). The overall aim of the SLT working with people with dysphagia includes a detailed

assessment and balancing safety with regards to swallowing with quality of life (RCSLT 2009). Participants were questioned about their experience of receiving a SLT service and asked to provide suggestions for improvement. Participant responses are discussed under the following three sub theme headings; *emotional response to SLT input, SLT communication* and *SLT future suggestions.*

4.4.1   Sub theme: Emotional response to SLT input

Half of the participants recalled elements of the SLT input they received. Jack provides a somewhat unenthusiastic narrative of his former SLT visit;

> *'yeah I remember, she said eat slowly not fast, [made me] angry, piss* off''.

Chris also recalls his SLT assessment experience negatively;

> *'[she] watched me eat, talked to me, she put me off'.*

Others describe their recollection of previous SLT input in a more impartial manner. When asked about past SLT input, Anuja used her VOCA to describe;

> *'drinks…coke…thickener….watch'*

The remaining participants struggle to recall the SLT visiting and the input they had received;

> *'can't remember, must have come but I don't know what she said'* (Mary).

4.4.2 Sub theme: SLT Communication

All participants who recall previous input volunteer information regarding the SLT's communication skills. Five of the six participants offer positive appraisals particularly in relation to the SLT communicating assessment results directly to them, as well as to their carer. Chris provides a positive account of when his SLT fed back to both him and his carer;

> *'she spoke to both of us, that's good'.*

Likewise, a sense of appreciation was expressed by Pam regarding the SLT's communication;

> *'yeah she talked to me about it, I like that'.*

Only one participant expresses a preference for the SLT to talk to their carer rather than to them;

> *'tell my sister, no not me, angry'(*Jack, male*)*

There is an overwhelming preference from adults with ID for the SLT to communicate their assessment findings directly to them. This may be due to the inequalities people with ID face when accessing health care (Ali et al. 2013). Adults with ID are often excluded from consultations due to communication difficulties (Ward, Nichols and Freedman 2010). It is unsurprising therefore that the participants in this study express a preference for the SLT to speak directly to them.

4.4.3 Sub theme: SLT suggestions

The majority of participants (75%) were keen to share ideas regarding suggestions for SLT service improvement. Participants identified a number of ideas ranging from eating together during assessments to offering a more individual person-centered service.

Interestingly, a number of participants offer the same single recommendation; for SLT's to eat with them during mealtime assessments. Helena uses her communication book to communicate her recommendation;

'eat…lunch…me…happy…watch'.

Identical suggestions were also provided by other participants;

'eat with me' (Paul)

'have lunch with me' (Chris)

People with ID often have few friends and experience social exclusion (Wilson et al. 2016). Eating with others is known to lead to an increase in social bonding and feelings of wellbeing (Dunbar 2017). This may go towards explaining why a proportion of adults with ID in this study suggest SLT eats with them during assessment.

Another single suggestion for service improvement was also offered by a number of participants; for SLT's to assess specific tasks before making final recommendations. Anuja, who is prohibited from eating her favourite food sausages, uses her VOCA to suggest;

'watch eat sausages….favourite…might not choked'.

Reflecting this, Ali who is unhappy about having his food cut up provides the following suggestion;

'I want her to sit and watch and erm watching me how I'm cutting it up, I can do it you

know'.

Similarly, Tracey who is currently assisted to drink makes the following request;

> *'see me holding my cup myself and have my drink'.*

Participant requests for more person-centred assessments suggest current practice can and needs to improve.

Other suggestions for improvement put forward by participants are as follows. Anuja proposes SLT's are involved in the cooking and modification of meals during assessment, a concept which is not currently standard practice;

> *'make and cook food, and mash food, make it right'*

Sitting further away during mealtime assessment is another suggestion put forward. Chris explains how the SLT put him off eating during his assessment and provides a solution;

> *'put me off, move away, another room'.*

A further proposal offered is in regards to the verbal advice provided by SLT. Pam astutely advises SLT to rephrase their verbal advice, telling people what they should do rather than what they should not do;

> *'tell me to eat slow, she said I eat fast, angry*'.

The final suggestion is in regards to the recommendation of the use of thickener. The clarity and simplicity of Jack's response makes it particularly striking. When asked what the SLT could do differently in the future, he simply states;

> *'the thickener, bin it!'.*

The remaining participants struggled to provide suggestions, giving answers such as *'I can't find an idea, sorry*' (Mary, female). The increased insight into and understanding of individuals perspectives regarding service improvements gained from interviews, will contribute to future service development.

4.5 Summary

Findings from this study generated the following four main themes; psychological responses to food and drink, independence, physical health consequences of dysphagia and SLT input. The psychological experience of adults with ID in relation to food and drink were by far the most frequent and poignant theme echoing throughout the interview data. Interestingly, much less

attention was given by participants to the physical experiences of having dysphagia. The relationship of the findings of this study will now be interpreted in relation to previous research carried out on this topic, along with limitations and reflexivity.

CHAPTER 5.0: DISCUSSION

This study was designed to explore the physical, social and psychological experiences of adults with ID living with dysphagia. The rich data acquired via semi-structured interviews provides new insight into such experiences reported directly from adults with ID and dysphagia themselves. This section will discuss the findings of the study and their relationship with current literature under the following three headings; psychological experiences of adults with ID and dysphagia, social experiences of adults with ID and dysphagia and physical health experiences of adults with ID and dysphagia. All three headings are aligned to the original study aim as identified above. The clinical implications of the findings will then be discussed in the context of existing dysphagia services. This will be followed by sections regarding limitations of the study and reflexivity and a chapter discussing clinical implications and recommendations for future research.

5.1 Psychological experiences of having dysphagia

The majority of findings from this study, which are discussed under separate headings below, relate to the psychological experiences of adults with ID and dysphagia.

5.1.1 Psychological effects of eating modified food textures

Negative emotions relating to modified food textures were reported by the majority of adults with ID in this study. Over half of the participants in this study expressed sadness, anger, embarrassment and frustration in regards to eating modified food textures. The findings of this study resonate with other studies. Comparable feelings of frustration, anger, sadness and depression have also been expressed by older adults on modified diets (Ullrich and Crichton 2015). Similarly, embarrassment features significantly in a literature review examining articles relating to experiences of dysphagia (Larsen and Uhienfeldt 2012). Although Dalton, Caples and Marsh (2011) claim dysphagia can negatively affect quality of life for adults with ID, there is a lack of supporting literature. The findings of this study however go some way to filling this gap in the literature.

5.1.2 Psychological effects of food limitations

The detrimental psychological effects of imposed food limitations were described by almost all participants with ID in this study. Negative emotional responses have been reiterated by adults with Cerebral Palsy and dysphagia who also report frustration in relation to loss of preferred

foods (Balandin et al. 2009). Additionally, the findings resonate with those of Martino, Beaton and Diamant (2009) in which patients report depression as likely when texture restrictions prohibit a favourite food. Depression has also been found common in people with Parkinson's disease and dysphagia (Plowman-Prine et al. 2009). Although the term '*depression'* is not uttered by adults with ID in this study, perhaps explained by the limited vocabulary skills of this population (Cumella 2016), the emotional states conveyed through their narratives can certainly be associated with feeling this way. The findings of this study are similar to other literature, yet add further insight into the thoughts and experiences of adults with ID indicating the loss of preferred foods due to dysphagia can also have a detrimental psychological effect on this client group.

5.1.3 Psychological effects of drinking thickened fluids

The findings of this study regarding the psychological responses to drinking thickened fluids depart from other literature. Only half of participants in this study dislike drinking thickened fluids. The remaining 50% are not opposed to having their drinks thickened. These findings run counter to the widely expressed distaste of thickened fluids (Beck et al. 2017, Lim et al. 2016). Such marked aversion is demonstrated by the results of a recent study which found people willing to sacrifice 4 years of their life rather than have to drink unthickened fluids (Lim et al. 2016). Nevertheless, the results of that study may have been influenced by the choice of non-dysphagic participants; individuals unacquainted with coughing and choking on normal thin fluids.

5.1.4 Psychological effects of reduced mealtime independence

Strong emotional responses associated with lack of control and independence at mealtimes are echoed throughout the study findings. The psychological impact of loss of independence due to dysphagia has also been reported by adults with Cerebral Palsy (Balandin et al. 2009). Adults with ID however expressed highly emotive responses specifically in relation to having food cut up by carers. Amongst others, feelings of anger and frustration were voiced regarding lack of opportunity to cut up their own meal. Interestingly, despite this subject rousing several emotional accounts from adults with ID, it remains absent in any other literature. Adults with ID are a vulnerable and often dependent population (WHO 2014, Hartley and MacLean 2008). Reducing further opportunities for independence i.e. by cutting up their food may only add to their sense of helplessness and dependency and thus explain the intensity of emotions expressed by this particular client group. The value placed on eating and drinking utensils by

adults with ID in this study supports this fundamental desire for independence; '[*my utensils mean] everything, mean everything to me* (Jack, male). Findings of this study indicate adults with ID place substantial value on mealtime independence and suggest it not only helps manage the speed and pace of meals for adults with ID (Wright et al. 2014) but also benefits individuals psychologically.

5.1.5 Psychological effects of receiving mealtime verbal prompts

The psychological effects of receiving verbal prompts at mealtimes were variable for adults with ID. Despite differing accounts, the findings add new insight into the perceptions of adults with ID and dysphagia on this topic. An estimated 78% of adults of ID receive prompting, pacing and supervision as a 'supportive' measure at mealtimes (Ball et al. 2011, p389). For one participant, the verbal prompts received from the SLT were reported to '*piss me off*'. The results of this study therefore question how supportive such prompts may be considered by adults with ID. There is very little literature researching individual preference for mealtime prompts. The findings of this study however suggest that prompts, commonly described by professionals as 'supportive', may not be viewed in the same way by adults with ID and in fact may have a detrimental psychological impact.

5.1.6 The predominance of psychological responses to dysphagia in the context of challenging behaviour

The psychological effects of dysphagia were by far the most frequently spoken about topic by adults with ID in this study. These exploratory findings are valuable in adding knowledge to the research field and the prevalence of such experiences expressed by adults with ID with dysphagia implies these consequences may be of greatest significance to this client group. This interpretation is reflected by the findings of Martino, Beaton and Diamant (2009) who found patients to prioritise the psychological consequences of having dysphagia over the physical.

Challenging behaviours such as verbal outbursts, self-injury and/or physical aggression are reported to be factors contributing to the need for mealtime support for 50% of adults with ID (Ball et al. 2011). The predominance of psychological responses to dysphagia, as revealed in this study, may contribute to the understanding of why such high incidence of challenging behaviours take place at mealtimes for adults with ID. Despite the drive to relocate people with ID to community-based care settings (Owuor et al. 2018), the assistance people with ID receive in their homes still has institutional qualities (Bjornsdottir, Stefansdottir and Stefansdottir 2015). Most people value the freedom to make choices about their lives and

many would challenge attempts to curtail it (Taylor 2014). The results of this study highlight this is no different for adults with ID. The anger and frustration reported by adults with ID and dysphagia in receipt of modified meals and 'supportive' mealtime prompts, expressed with reduced communication skills (RCSLT 2013) may provide some insight into the source of mealtime challenging behaviours for this client group.

5.2 Social Experiences of having dysphagia

It is well established that eating is a social experience (Fieldhouse 1995). Eating out in public however was described as unenjoyable for almost half of the adults with ID and dysphagia. These findings add new insight into the social experiences of adults with ID yet resonate with those reported by other client groups with dysphagia. Similar to others, adults with ID report feeling '*uncomfortable'* and '*embarrassed'* when eating out (Paris et al. 2012, Farri, Accornero and Burdese 2007).It is well documented that dysphagia can lead to feelings of embarrassment regarding eating and consequent social isolation (Leow et al. 2010, Balandin et al. 2009, Watt and Whyte 2003) so much so that elaborate strategies are often used by people with dysphagia to avoid eating meals in public (Martino, Beaton and Diamant 2009, Ekberg et al. 2002).

The findings of this study suggest adults with ID are also vulnerable to feelings of embarrassment, which may result in increased social isolation. This is a particularly concerning finding for a population who already face high levels of social exclusion (Owuor et al. 2018) and experience higher prevalence of mental health conditions than the general population (Cooper et al. 2007). Socialising with others is known to benefit both mental and physical health (Cohen 2004). It is imperative therefore that adults with ID who already have increased risk of mental health difficulties, continue to eat out and socialise with others. The findings of this study however suggest that due to dysphagia, adults with ID are in danger of experiencing additional social exclusion and therefore increased mental health difficulties.

Despite the detrimental social and psychological consequences of dysphagia experienced and reported by adults with ID in this study, all participants report they still enjoy eating. These findings conflict with those of other studies in which participants with dysphagia report they no longer find eating pleasurable (Farri, Accornero and Burdese 2007, Ullrich et al. 2014). Mealtimes however are important not only for adequate nutrition but also for social interaction (Balandin et al. 2009). Despite the undesirable effects of dysphagia, the findings

from this study suggest adults with ID may nonetheless enjoy eating due to the increased social interaction and engagement mealtimes can offer.

5.3 Physical health experiences of adults with ID and dysphagia

Current dysphagia management focuses on reducing the physical health risks of dysphagia. As stated in the RCSLT resource manual for commissioning and planning services for dysphagia (2009: 7), 'considering the safety of the swallow, managing aspiration and preventing complications are of paramount concern'. With this in mind, It is particularly interesting that participants in the study refer only briefly to their experiences of physical health consequences of dysphagia in comparison to the abundance of narrative relating to the psychological and social consequences of dysphagia. One interpretation of this could be due to physical health consequences such as episodes of coughing, choking and pneumonia being commonly asked about during case history, participants do not feel they need to talk about this topic. The findings may indicate that due to adults with ID not commonly being asked about their feelings towards having dysphagia, this led to them being much more verbose on this rarely spoke about topic.

5.4 Limitations of the study

It must be stressed that this study is primarily concerned with adults with mild to moderate ID. Despite providing new insight, the research is exploratory in its findings. There are still gaps in our knowledge regarding the experiences of adults with ID and dysphagia, particularly those of adults with severe and profound ID. The small number of participants involved in this study means the findings are not representative of this client group as a whole. Data collected from non-verbal participants was influenced by the vocabulary available on their communication aid.

Participants varied in regards to the length of time which had passed since their dysphagia diagnosis was made and recommendations implemented. As a result, some participants may have only recently had changes made to their food and drink whereas for others the changes may be already longstanding. The experiences expressed by those only recently undergoing changes may be different from others.

Despite limitations, the noticeable gap in the literature regarding the experiences of adults with ID and dysphagia has started to be addressed by this study. A great deal of further

research however is needed to get a more in depth understanding of the experiences of adults with ID and dysphagia.

5.5 Reflexivity

As an SLT registered with the HCPC and RCSLT, reflexivity is core to my practice. Completing this research study has been a valuable learning experience. Not only have I gained a true understanding of the barriers, frustrations and rewards of the research process, but I have also re-evaluated my own clinical practice based on the study findings.

The completion of interviews itself was a steep learning curve. I found the act of interviewing to be an iterative process and I grew in confidence the more interviews I carried out. The skills of supporting clients with communication needs to answer interview questions without prompting or directing them too much was challenging but a skill I developed through the process of completing more interviews. Unfortunately, the use of photo elicitation did not add much to the research findings. With hindsight, it may have been more beneficial to use the photographs taken by participants at the start of the interview as a conversation starter. Using the photographs at the end of the interview schedule meant that the topic had already been covered and therefore the data was somewhat redundant.

There were challenges which came with interviewing a vulnerable population group with communication difficulties. The rich data obtained from the participants however proves that it can be done. The use of familiarisation sessions was extremely helpful in tuning into individual's receptive and expressive communication levels. Involving participants who use AAC to communicate did impact on data collection. They had limited vocabulary access therefore answers were somewhat influenced by the symbols available to them. The familiarisation sessions however helped to identify any vocabulary that needed to be added to their communication aid to support interview access.

I found the results of this study surprising, particularly in relation to the anger and upset reported by participants caused by having their food cut up by others. I was shocked to hear that a technique commonly recommended by SLT to reduce the risk of choking for the ID population created such intensity of emotional distress to individuals. As an SLT I have already changed my practice and strive to find alternative, more empowering ways for individuals with ID to reduce their risk of choking. Operating with some praxis as a researcher, I found it challenging to step aside from the emotions attached to being professionally shocked. Iteratively and in particular during the analytical stages and feedback provided from the

service users enabled me to step more fully into my researcher role. This has been built upon and I can evidence this as this research process has encouraged me to work with psychology services within the ID service and develop their role in the dysphagia MDT. I have recently started joint-working with a psychologist to produce trust guidance regarding psychological input to dysphagia services for adults with ID.

CHAPTER 6.0: CLINICAL IMPLICATIONS

The results of this study have clinical implications for professionals working with adults with ID and dysphagia. Developing recommendations for services working with adults with ID and dysphagia is an objective of this study and will now be discussed.

Firstly, the findings of this study indicate the negative psychological and social impacts of dysphagia as experienced by people with ID. Consequently, it is suggested that service involvement for adults with ID and dysphagia should be re-evaluated in light of these new exploratory findings. Current guidance for professionals in the management of dysphagia focuses primarily on minimising physical risks (RCSLT 2009). This is evident in the following statement regarding SLT role in dysphagia;

> *'SLT are involved in environmental modifications, safe swallowing advice,*
>
> *appropriate dietary modification, and the application of swallowing strategies, which*
>
> *improve the efficiency of swallow function and reduce the risk of aspiration'*

(RCSLT 2009 p11).

The results of this study however indicate there is greater need for services to focus additionally on limiting any detrimental psychological and social effects of dysphagia. Although previously acknowledged that dysphagia can contribute to a reduced sense of wellbeing for adults with ID (Howesman 2013), little direction has been provided as to how individuals' wellbeing can be supported. The results of this study however support the recommendations proposed by Nund et al (2014); for the physical, social and emotional consequences of dysphagia to be addressed for adults with HNC and dysphagia. Likewise, the findings of this study suggest adults with ID will also benefit from services offering equal consideration of the physical, social and psychological aspects of dysphagia. Figure 4 below has been developed as a visual representation of this finding;
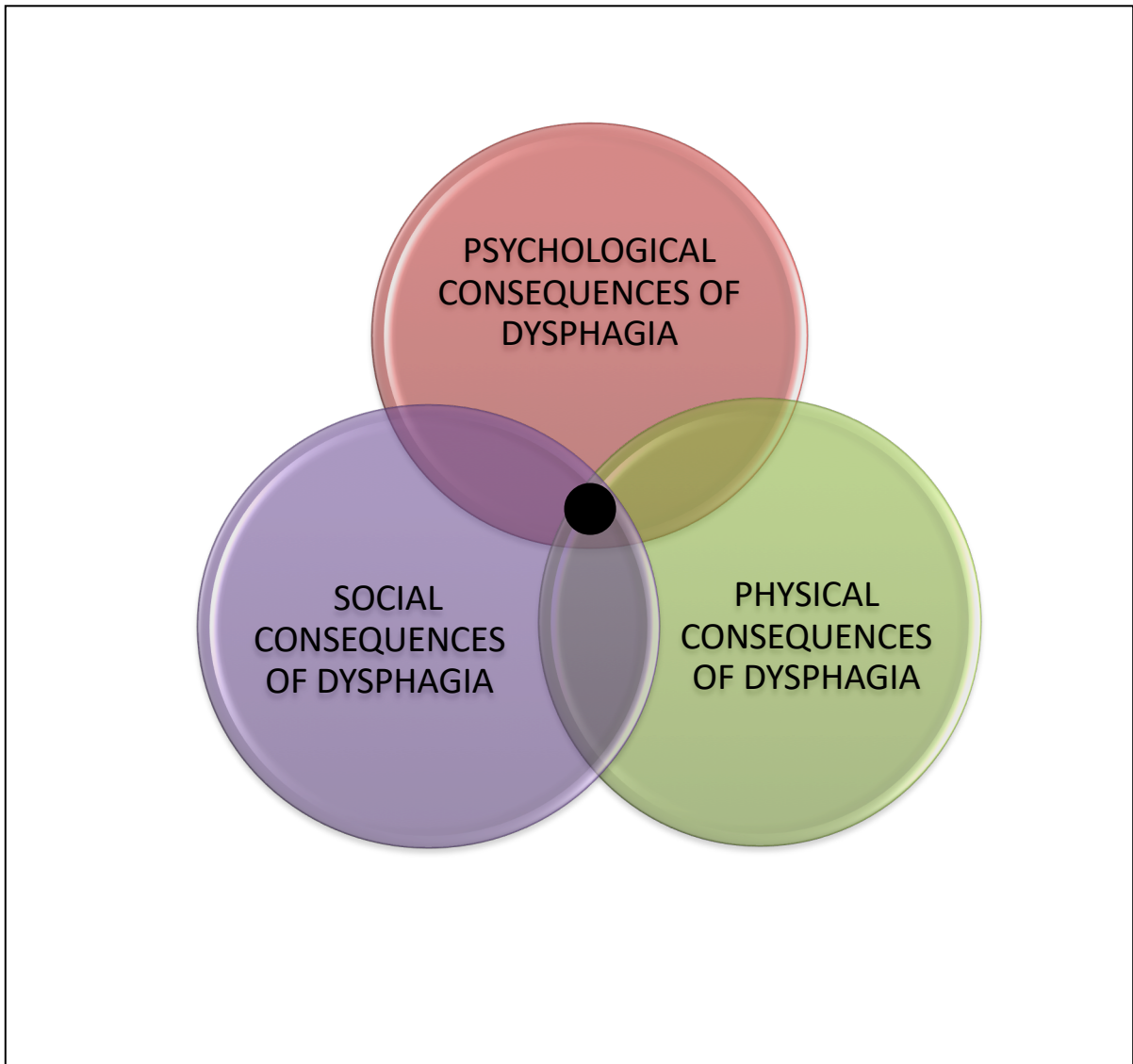
●= Individual with dysphagia

Figure 4: Consideration from services for the individual with dysphagia.

The individual with dysphagia has been placed in the centre of the model to receive services which address not only the physical aspects of dysphagia but also the social and psychological. Incorporating this model into standard practice may not only lead to reduced feelings of sadness, frustration and challenging behaviours but also foster greater feelings of autonomy and inclusion for adults with ID and dysphagia. Suggestions centred on direct participant feedback and supporting literature, for how services can address the psychological and social effects of dysphagia, will now be offered.

6.1 Addressing the Psychological aspects of dysphagia

The findings of this study suggest a number of ways in which the psychological aspects of dysphagia can be addressed;

6.1.1 Clinical Psychology Input

The role of a clinical psychologist is to improve patients' quality of life (Wahass 2005). It has been previously reported that psychologists can support individuals in the management of the emotional effects of dysphagia (Dalton, Caples and March 2011). Despite this, psychology services rarely form part of the multidisciplinary team (MDT) which supports people with dysphagia (Logemann 1994). The findings of this study however indicate that individuals with dysphagia may benefit from psychology services becoming part of the core MDT, particularly those with ID already vulnerable to mental health conditions.

6.1.2 Support Networks

Support groups can positively influence management of chronic ill-health conditions and contribute to successful adaptation (Brunelli, Murphy and Athanasou 2016). The results of this study indicate that peer support networks may be beneficial in supporting the psychological needs of people with dysphagia. Along with offering psychology services, support groups could be set up, to which newly diagnosed individuals are signposted for psychological support. There is currently no research completed regarding effectiveness of support groups for adults with ID and dysphagia.

6.1.3 Person-Centred dysphagia Care

In line with the values of DoH (2012), patients are to take part in shared decisions in all aspects of their care. Services should ensure adults with ID and dysphagia are offered choice at every opportunity during their dysphagia journey. As recommended by a number of participants in this study, person centred assessments could be provided i.e. individuals observed eating favourite foods to prevent unnecessary diet restrictions. Similarly, individual preference regarding the use of thickener must also be considered and alternative strategies (Panther 2005, Bülow, Olsson and Ekberg 2003) considered where appropriate.

Professionals need to be aware of their own beliefs regarding the impact of mealtime prompts on individuals. Patients are experts in their own lives and should be consulted, no matter how insignificant the decision may appear, to ensure individual based care is provided. Adults with

ID should be involved in decisions regarding preferred mealtime prompts. New and alternative methods for prompting and pacing such as the use of vibrating pagers (Ercheverria and Miltenburger 2012), should be explored.

As recommended by participants, individual preference regarding SLT proximity during the dysphagia assessment must be sought. Similarly, the option of eating together during assessment should be offered. Assessment results and management plans should be discussed with both client and carer. Services should ensure information regarding dysphagia is shared with adults with ID to allow those with the mental capacity to do so, to make informed decisions regarding mealtime recommendations. Mealtime independence should be maximised. Services should make every effort to empower this already vulnerable population. Increasing independence at mealtimes may not only lead to reduced associated health risks for adults with ID but increase feelings of empowerment.

6.2 Addressing the Social aspects of dysphagia

Recommendations of how services can support individuals with the social aspects of dysphagia will be discussed under the following two headings; environmental support and individual support.

6.2.1 Environmental support

Individuals with ID continue to have an increased community presence; living and accessing more services in the community (Owuor et al. 2018). As per the Equality Act (2010), reasonable adjustments should be made for people with dysphagia. There is limited evidence however of such modifications and very few cafes / restaurants cater for people with dysphagia. As reported by Owuor et al. (2018), unless community living for people with ID is enhanced by all means possible, there is a risk of 'redistributing' institutional isolation to the community rather than progressing genuine social inclusion into the community. The findings of this study suggest that services can contribute to increased social inclusion for adults with ID and dysphagia. SLT services play a role in advocating social inclusion in the community (RCSLT 2003). The findings of this study suggest adults with ID and dysphagia would benefit from the advocacy of 'dysphagia friendly' cafes and restaurants. In line with the social model of disability, services should consider providing training to cafes / restaurants and encourage modified meals to be added to menus as standard. Similar to gluten free and vegan meals, symbols could be utilised nationally on menus to indicate meals available in mashed or puree consistency. Consideration must however be given to the cost implications of delivering such

services as financial pressures are in part a factor for driving change throughout the NHS (NHS England 2017). A campaign (#dysphagiafriendlyclub) via the researcher's active Twitter account may be a great vehicle to "kick start" the introduction of dysphagia friendly dining and will be developed as part of the research dissemination plan.

6.2.2 Individual Support

The findings of this study suggest individuals with dysphagia may benefit from direct support and advice regarding eating out socially. The psycho-social impact of having dysphagia must be proactively acknowledged and addressed by services working with adults with ID and dysphagia. Advice for eating out socially could be provided as standard to help reduce feelings of embarrassment and reduce risks of social isolation as indicated in the findings of this study. Considerations for clinicians are shared in Table 5 below.

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o   Advise the individual with dysphagia to sit with their back to the café / restaurant to reduce any embarrassment regarding modified food and drink.

o   Advise the individual to choose foods from the menu which are the appropriate texture in their natural form.

o   Advise the individual and their carers to contact the café / restaurant in advance to explain individual eating and drinking requirements. This will reduce discussion once there.

o   To avoid food modification taking place at the table, advise individual to request for their meal to be modified to the appropriate texture in the kitchen prior to being served. Information about the target food texture could be printed on a pre-prepared card and handed to the waiting staff to reduce discussion when there.

Table 5: Considerations for clinicians working with adults with ID and dysphagia.

The above recommendations could also be offered directly to individuals with ID and their carers to aid the experience of eating out socially with dysphagia, see table 6 below;

> - o If you feel a little embarrassed about eating out, some people like to sit with their back to the other people in café / restaurant.
> - o If you feel embarrassed about mashing or pureeing your food in public, some people choose foods from the menu that are already safe to eat e.g. mashed potato, fish pie, soup. You will be able to look at a menu online before you go to see if there are any options for you.
> - o Another option is to ask the staff to mash or puree your meal in the kitchen before they bring it out to you.
> - o If you feel embarrassed telling the staff in a café/ restaurant about your dysphagia, you could phone them before you go and explain how you need your food and drink to be prepared. Or some people prefer to have the information written down on a piece of card which you can hand to the staff when you arrive.

Table 6: Advice for individuals with dysphagia regarding eating out socially

An overall summary of recommendations for services working with adults with ID and dysphagia can be found in appendix 11. Implementation of suggested recommendations may also prove beneficial for other marginalised groups with dysphagia i.e. those with Parkinson's disease of which more than 80% develop dysphagia during the course of their disease (Suttrup and Warnecke 2016) and people with dementia of which 68% develop dysphagia (Steele et al. 1997).

6.3 Recommendations for future research

Research is vital in providing new knowledge required to improve health outcomes and reduce inequalities (DoH 2010). More research is needed with adults with ID and dysphagia but on a larger scale. Despite the challenges of including adults with ID in research, this study highlights that with methodological adjustments, rich data can be acquired from this under-represented population. Including adults with ID in future research on this topic will further enhance our understanding of their experiences first hand. Recommendations for future research are indicated below;

- The difference in experiences across differing levels of ID's should be investigated in order to find out if people with more severe ID have different experiences. Observations of those with more severe and profound disabilities will provide more insight into the experiences of adults with ID.

- The relationship between mealtime challenging behaviour and dysphagia management plans is another area yet to be researched. Researching the impact of changes to dysphagia plans on individuals' challenging behaviour levels would add insight into the relationship.

- Another possible area for investigation includes researching the opinions of adults with ID on the use of food moulds. Other client groups have responded positively towards moulded texture modified food (Ullrich et al. 2014) therefore it would be interesting to compare the perspectives of the ID population.

- Research into the usefulness of mealtime verbal prompts with adults with ID and investigation of alternatives should be completed. Limited research has been completed on the reception of verbal prompts at mealtimes for adults with ID.

- It is important to investigate the efficacy of the support recommended by this study for adults with ID and dysphagia. Future research could focus in particular on the benefits of receiving psychological support during dysphagia assessment and management for adults with ID and the effectiveness of dysphagia support groups.

- The benefits and barriers of SLT eating with clients during assessment is another area yet to be researched.

- In support of Barnes and Sheldon (2007: 11), disability research should ensure the 'disabling society' is also examined. Inviting representatives from cafes and restaurants to take part in research regarding the benefits and barriers to creating 'dysphagia friendly' environments would increase knowledge so a truly inclusive society for individuals with dysphagia can be achieved.

6.4 Conclusion

The thesis aimed to explore the physical, social and psychological experiences of adults with ID and dysphagia. Although exploratory in its findings, this study achieved its aim and can contribute new knowledge to the literature relating to adults with ID and dysphagia. The findings indicate that in addition to the known physical risks posed by dysphagia, adults with ID may also experience detrimental psychological and social consequences.

Adults with ID and dysphagia are placed at increased risk of social exclusion due to embarrassment when eating out. Additionally, undesirable modified meals, loss of preferred foods, reduced mealtime independence and unwelcome mealtime support may lead to adverse psychological consequences. The tentative link between mealtime challenging behaviours and frustration towards dysphagia management plans indicated by the study findings must be explored further.

Despite ethical challenges, adults with ID can and must continue to be included in research. The benefits of involving adults with ID in research outweigh any difficulties experienced. With methodological adjustments, adults with ID both with and without verbal speech can be supported to successfully and meaningfully participate in qualitative research.

The study findings suggest implications for policy and practice. There is a need for services to address not only the physical risks of dysphagia but also the social and psychological consequences. Working alongside psychology services, providing more person centred care and facilitating an inclusive society will benefit adults with ID and dysphagia. Should these recommendations be implemented, increased feelings of inclusion, empowerment and independence with reduced feelings of frustration, sadness and social exclusion may be experienced by adults with ID and dysphagia.

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Appendix 1 – Literature Search details

Search 1: Literature relating to adults with Intellectual Disability and Dysphagia

Databases searched in October 2017 included Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE and PSYCHINFO. The last fifteen years (2002-2017) was selected as dysphagia within the ID population was emerging at that time as a clinical need affecting lifestyle.

Inclusion - Papers considered for inclusion by title and abstract were initially screened: qualitative and quantitative articles published between 2002 and 2017.

Exclusion - Articles published before 2002 and/or relating to either the paediatric population, or those with mental health difficulties were excluded.

CINAHL

Subject headings used:

Mentally disabled

Intellectual disability

Mental retardation

Learning disability

AND

Dysphagia

Deglutition

MEDLINE

Subject headings used:

Mentally disabled

Intellectual disability

AND

Deglutition disorders

Article titles and abstracts were reviewed and any appropriate articles were read in full. Reference lists of such articles were also studied for other relevant articles.

Search 2: Literature relating to experiences of adults with dysphagia who do not have intellectual disability.

Databases searched in October 2017 included Cumulative Index to Nursing and Allied Health Literature (CINAHL) and MEDLINE. The last fifteen years (2002-2017) was selected as it is important within gaining a robust understanding of others' experiences of dysphagia.

Inclusion- Papers considered for inclusion by title and abstract were initially screened: qualitative and quantitative articles published between 2002 and 2017.

Exclusion - Articles published before 2002 and/or relating to either the paediatric population, or those with intellectual disability or mental health difficulties were excluded.

CINAHL

Subject headings used:

   Dysphagia

   Deglutition

                                          AND

   Attitude to illness

   Patient attitudes

   Quality of life

MEDLINE

Subject headings used:

   Dysphagia

   Deglutition disorders

                                          AND

   Quality of life

Article titles and abstracts were reviewed and any appropriate articles were read in full. Reference lists of such articles were also studied for other relevant articles.

Search 3: Literature relating to involving adults with intellectual disability in research.

Databases searched in October 2017 included Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE and PSYCHINFO as it is important to gain an understanding of the different ways in which adults with ID can be included in research.

Inclusion - Papers considered for inclusion by title and abstract were initially screened: qualitative and quantitative articles published between 2000 and 2017.

Exclusion - Papers published before 2000 and/or relating to the paediatric population were excluded.

CINAHL

Subject headings used:

Mentally disabled

Intellectual disability

Mental retardation

Learning disability

AND

Research subject recruitment

Research dropouts

Research subject retention

MEDLINE

Subject headings used:

Intellectual disability

Mentally disabled

AND

Research subjects

PsychINFO

Subject headings used:

Intellectual developmental disorder

Cognitive impairment

Developmental disabilities

AND

Research subjects

Article titles and abstracts were reviewed and any appropriate articles were read in full. Reference lists of such articles were also studied for other relevant articles.

[Justification for each statement and question included are typed in italics in square brackets]

1. **Demographic Information**

Interview Number:………………………………………………………….

Sex……………………………………………………………………

Age:………………………………………………………………..

Ethnicity:………………………………………………………..

Residential Setting……………………………………………..

Date of interview………………………………………………

2. **Introduction**:

Hi x. Thank you for coming to talk to me.

How are you today?

[building rapport with interviewee]

This study is about your experiences of having dysphagia; difficulties with eating and drinking.

[setting the scene]

I will be recording our conversation today. Is that ok?

[gaining consent again]

I might write some things down too. Is that ok?

[gaining consent again]

I will keep the recording and my notes safe.

No-one will know what you have said to me.

But if I think you have been treated badly then I will have to tell somebody.

[reminding interviewee of confidentiality]

We can stop for a break at any time.

Tell me when you want a break.

[to help interviewee feel comfortable]

You can stop talking to me at any time.

Tell me if you want to stop.

[reminding interviewee that they can opt out at any time]

Do you have any questions about what we are doing before we start?

[building rapport]

Ok, we're going to talk about your eating and drinking.

[setting the scene]

3. **General information**

- **Tell me a bit about your eating and drinking?**

[open question, not too threatening]

- **Do you like eating and drinking?**

- **Why? Why not?**

4. **Food Textures**

- **Do you change how your food looks before you eat it?**

- **In what way?**

- **How do you feel about this?**

asking about emotional consequences – Nund et al. 2014, Paris et al. 2013].

- **How do people help you with this?**

- **How can people help you more with this?**
  [more detailed questions, cueing them into the topic]

- **What is it like eating in public like at the pub?**
  [more detailed questions, asking about psychosocial needs – Nund et al. 2014, Paris et al. 2013)]

- **Are there foods you would like to eat that you can't?**

- **How do you feel about this?**

Are you happy to carry on talking to me?

       Would you like a break?
       [takes the burden off the participant to remember and articulate this request to the researcher.]

5. <u>Drinks textures</u>

- **Do you change how your drink looks before you drink it?**

- **How?**

- **How do you feel about this?**
  [asking about emotional consequences – Nund et al. 2014, Paris et al. 2013].

- **How do people help you with this?**

- **How can people help you more with this?**
     [more detailed questions, cueing them into the topic]

- **What is it like drinking in public like at the pub?**

[more detailed questions, asking about psychosocial needs – Nund et al. 2014, Paris et al. 2013

- **Are there drinks you would like to drink that you can't?**

- **How do you feel about this?**

Are you happy to carry on talking to me?

Would you like a break?

[takes the burden off the participant to remember and articulate this request to the researcher.]

6. Speech therapy input

Do you remember when your speech therapist x came to see you?

What did they say to you?

How did they tell you?

[method of info delivery – Brockbank et al. 2015].

How do you feel about this?

What did they do to help you with this?

How can they have helped you more with this?

[more detailed questions] (nund et al. 2014. Brockbank et al. 2015).

Are you happy to carry on talking to me?

Would you like a break?

[takes the burden off the participant to remember and articulate this request to the researcher.]

7. Photo elicitation

- **You took this photo… What does this mean to you?**

[Referring to photo elicitation Banks, 2001]

8. Summary

Is there anything else you'd like to tell me about having dysphagia?

[ending on an open question in case anything has been missed]

Thank you for talking to me. It's been really helpful

[summarising end of interview]

You will get a certificate in the post to say you have taken part in research

[*confirmation*]

If you are worried about anything we have talked about please tell me. I can refer you to a speech therapist for further advice *[making sure interviewee feels ok]*

It was lovely to meet you. Thank you *[end of interview]*

Phase	Example of data analysis at each phase
1. Familiarising self with data	Interviews transcribed and initial ideas noted down e.g. psychological responses to being dependant on others features heavily particularly in relation to being assisted and having food cut up.
2. Generating initial codes	- Foods not allowed to eat anymore - Negative emotions regarding being assisted to eat - Want to cut up own food - Opinion on drinking thickened fluids
3. Searching for themes	Themes: Food and drink? Being fed? Being helped?
4. Reviewing themes	Initial codes linked to potential themes – Foods not allowed = food and drink? Thickened fluids = food and drink? Negative emotions regarding being assisted to eat = being fed? Want to cut up own food = being helped? Ideas checked with supervisor
5. Defining and Naming Themes	Cutting up food and being assisted to eat fall under a broader heading of independence. Foods not allowed and opinions of thickened fluids fall under broader theme of psychological responses to food and drink. 4 main themes defined and named: Psychological response to food and drink Independence Physical health consequences of dysphagia SLT
6. Producing the Report	Interview extracts relating to each theme fed back in report; e.g. Theme- Independence, Sub theme - Being assisted: *"they feed me too quick…it's horrible…I could choke"* (Tracey, female)

Initial and final descriptor themes:

Initial descriptor themes	Final themes with subthemes
Food and drink? Eating out?	Psychological responses to food and drink - Prohibited Foods - Modified food textures - Thickened fluids - Eating out socially
Being fed? Being helped?	Independence - Being assisted - Utensils - Cutting up food - Verbal prompts / observations
Choking?	Physical Health Consequences of dysphagia - Choking - Weighing up of information
Recommendations?	SLT services - Emotional and psychological response to SLT input - SLT communication - SLT future suggestions

A coded interview extract illustrating the application of thematic analysis:

Interviewer (I): Do you cut up your own food?

Participant (P): No they don't trust me. I wish they did [3 secs] make me feel uncomfortable (Ind)

I: why?

P: Cus when other people are eating normal food but not me [4 secs]embarrassing (soc) [5 secs] All I want is like erm I want to do it myself (Ind)

I: How does that make you feel?

P: they think I'm a baby. I get so frustrated I get really upset. (psych) If I need some help I'd ask. I can do it myself (Ind)

I: How does it feel when you do it yourself?

P: It make me feel better in myself but they won't let me do it. (Ind)

I: Are there any foods that you'd like to eat that you can't?

P: some yeah

I: Which ones?

P: sweets. But I can eat one in a room with somebody so they can keep an eye on me. I don't mind that.(Obs)

I: What foods would you like to eat that you can't?

P: Kidney beans. They get stuck (Phys) and I can't get them out.(prohib)

I: How does it make you feel that you can't eat kidney beans?

P: Awful (psych)

Codes (from extract above)
Ind = Independence
Soc = Social effects
Psych – Psychological effects
Obs = Observations
Phys = physical health consequences
Prohib = Foods prohibited to eat

Main Themes	Sub Themes	Participants											
		Mary	Jack	Pam	Samia	Jasmin	Paul	Ali	Anuja	Chris	Helena	Peter	Tracey
psychological responses to food and Drink	Prohibited foods	●	●	●	●	●	●	●	●	●	●	●	●
	Modified Food textures	●	●	●	●	●	●	●	●	●	●	●	●
	Thickened Fluids			●	●	●			●	●		●	●
	Eating out socially	●	●	●	●	●	●	●		●	●	●	
Independence	Being assisted			●	●		●	●					●
	Utensils					●	●		●				●
	Cutting up food	●		●	●			●	●	●	●	●	
	Verbal Prompts and observation				●					●			
Physical health consequences of Dysphagia	Choking	●	●			●	●	●		●		●	●
	Weighing up of information		●		●		●	●		●			●
Speech and Language Therapy	Emotional Response to SLT input		●	●	●	●	●	●		●			

(SLT)	SLT communication		●	●	●		●	●		●			
	SLT future suggestions		●		●		●	●		●			●

Research Title:

What are the experiences of adults
with intellectual disability and
dysphagia?

An exploratory study

Some
materials
have been
removed due

Research Aim and Objectives

Aim: To explore the physical, social and psychological
experiences of adults with ID and dysphagia.

Objectives:

- To develop recommendations for services working with adults
  with ID and dysphagia
- To provide a platform for a marginalised group of people to
  voice their opinions on a topic which is absent in the literature
- To promote inclusive research with adults with ID

Some materials
have been
removed due to
3rd party

Data collection tool

Semi-structured 1:1 interviews

Photo Elicitation (Harper 2002):

Participants will be asked to take photographs that
represent what it is like living with dysphagia. These
photographs will then be used to facilitate discussion
with that individual during their interview.

Participants

Purposive Sampling technique (Bowling 2014): focusing on a specific population that are of direct relevance to answering the research question.

> ## Inclusion Criteria:
>
> - Diagnosis of ID and Dysphagia
> - Received a community dysphagia service from the local community trust between 2007 and 2017
> - 19 years of age or over when they received the dysphagia service
> - Have the mental capacity to consent to participate in the study

Exclusion Criteria

Participants must:

- Not have received a community dysphagia service directly from the researcher
- Lack the mental capacity to consent to participate in the study

Recruitment

Participants will be recruited via trust DANS group.

- Clinician's to provide study information sheet to service users who meet the inclusion criteria and their significant other.
- Clinician to contact service user and significant other one week after providing study information to ascertain if they would like to take part and to complete initial interest in taking part form.
- SLT will contact potential participant on receipt of signed initial interest form

Dissemination of findings

- A final report will be written
- An easy read version of this report will also be available
- Share findings and recommendations with various relevant clinical networks
- Publishing – RCSLT Bulletin, Journal

Any Questions?

Learning about the experiences of adults with Intellectual Disability and Dysphagia.

What is this study about?

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancester Library - Coventry University.

You are invited to take part in a study.

I want to learn about your experience of having dysphagia.
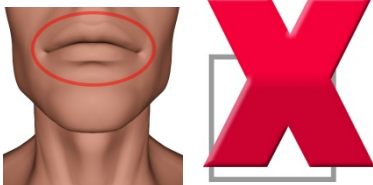
Dysphagia is when eating and drinking is difficult.

Why have I been asked to take part?

You have been asked to take part because you have dysphagia.

How will it help me?

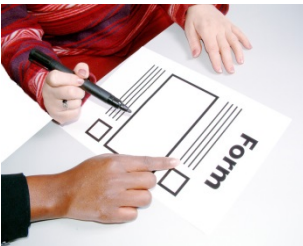I hope you will enjoy taking part in the study.

I hope that the study will help people understand more about the experiences of having dysphagia.

I hope it will help make services better for people.

What information will I be asked for?

You will be asked to fill in a consent form.

This form will ask you if you would like to take part in the study.

You will be asked to meet up with me and talk about your experiences of having dysphagia.

You can choose where we meet.

I will ask you about your eating and drinking.

I will ask you what you think about the food and drink you have.

I will ask you how people help you at mealtimes.

I will ask you how people can help you better at mealtimes.

You will be given a disposable camera and asked to take photographs of what it is like living with dysphagia.

We will talk about the photographs you have taken.

You are not allowed to take photographs of other people.

You can bring someone with you to our meeting if you would like to.

I would like to record our meeting. I will show you the recorder.

I would like to write down what you say.

I will not use your name when I write what we talked about.

The recording and notes will be kept safe. They will be kept for 5 years.

After 5 years, the recording and notes will be thrown away.

Taking part in this study will not affect your care.

You will get a certificate and thank you letter

for taking part in this study.

Do I have to take part in the study?

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancester Library - Coventry University.

No. You choose if you want to take part.

If you do not want to take part, that is ok.

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancester Library - Coventry University.

If you want to take part and then change your mind, that is ok.

You can stop taking part at any time.

Will you tell anyone if I take part in the study

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancester Library - Coventry University.

My research team will know you are taking part.

If you would like someone to come to the meeting with you, they will know too.

I won't tell anybody else what you tell me.

If you tell me that you have been harmed, I

will have to tell someone. This is to help keep

you safe.

Where will my information go?

I will use what you tell me to write a report.

I might use your words in my report.

No-one will know your name.

How will I find out the results of the study?

I will send you a leaflet which will tell you what

found out.

What do I do if I'm unhappy with how the study has been carried out?

You can contact my research team on

02477 655886.

What do I do next?

If you would like to take part in the study, please

fill in the "I am interested in taking part" form.

When I get the form, I will phone you.

My name is Rachael.

Thankyou for reading this information sheet.

This information sheet was written in conjunction with the XXXX Steering Group.

Interested in taking part in the study form

Some materials have been removed due to 3rd party copyright. The unabridged version can

I am interested in taking part in the study called

"What are the experiences of adults with intellectual disability and dysphagia?"

I am happy for the researcher to see my data.

I am happy for the researcher to phone me to talk about taking part in the study.

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancester Library - Coventry University.

I know I don't have to take part in the study.

I know that I can change my mind about taking part in the study.

I am interested in taking part in the study.

Your name………………………………………………………………..

Your signature……………………………………………………………

Today's date………………………………………………………………

Clinician's name………………………………………………………..

Clinician's signature……………………………………………………

Today's date………………………………………………………………

Study Title: What are the experience of adults with intellectual disability and dysphagia?

Consent Form

1. Have you read the information sheet about the study?

   (Please circle)

   Yes   No

2. Do you understand the information about the study?

   (Please circle)

   Yes   No

Please read the information below.

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancester Library - Coventry University.

I know it is up to me if I take part in the study.

I have been given the chance to ask questions about the study.

I know my conversation with the researcher will be recorded.

I know my words might be used in a report.

I know that I can stop taking part in the study at any time.

I know I can ask to receive a leaflet about the results of the study.

3. **Would you like to take part in the study?**

   (please circle)

Yes   **No**

Your name………………………………………………………………………

Your signature…………………………………………………………………

Today's date……………………………………………………………………

Clinician's name………………………………………………………………..

Clinician's signature…………………………………………………………

Today's date………………………………………………………………………

[Filing: 1-medical records; 1-participant copy; 1-site file]

This consent form was written in conjunction with the XXXXX Steering Group.

Notification of Confirmation of Capacity and Capability

Dear Miss Rachael Kasch,

Study Information	
Research Title:	What are the experiences of adults with Intellectual Disability and Dysphagia? An exploratory study.
Sponsor:	Coventry University
Lead Researcher:	Miss Rachael Kasch - Speech Language Therapist for Adults with Learning Disabilities, XXXXXXXXXXXXXXXXXX NHS Foundation Trust - Master student at Coventry University
XXXX Trust Ref.:	BCHCLearn233048.NonPortfolio
IRAS Ref.:	233048

XXXXXXXXXXXXXX Healthcare NHS Trust has reviewed your application for the research study described above. The review was based on the information described in the application form, protocol and supporting documents. The documents reviewed are listed below:

Document:	Version:	Date:
HRA Approval Letter	-	**08.12.2017**
HRA REC Favourable Opinion Letter	-	**08.12.2017**
IRAS form	**233048/1140562/37/793**	**Chief Investigator - signed 24/10/2017** **Sponsor – signed 20.10.2017** **Academic Supervisor – signed 20.10.2017**
Protocol	**V2**	**30.08.2017**
Initial interest in participation form	**V1**	**15.11.2017**
Easy Read PIS	**V5**	**01.12.2017**
Consent Form	**V4**	**01.12.2017**

Interview Schedule	V2	15.09.2017

Confirmation of Capacity and Capability

XXXXXXXX Healthcare NHS Trust is pleased to confirm that the Trust has the capacity and capability to deliver your research as per the Statement of Activities attached.

Your research can commence as of today (10.01.2018).

Please ensure you notify the R&I team with the following information:

1. Any amendment made to this research.
2. Any incident or complaint relevant to the conduct of the research within this Trust. This includes any event that could have, or did, lead to loss of data, a confidentiality breach, damage to property, and/ or harm to participants.
3. When all data has been collected.
4. As summary of the research findings, when available.

Please contact the R&I team if you need any support with your research or if you have any queries regarding the above.

May we take this opportunity to wish you success with your research.

Kind regards

Research & Innovation

XXXXXXXXXX NHS Foundation Trust

research.innovation@XXXXXX.nhs.uk

XXXXXXX

Research and Innovation Manager

Appendix 10 –HRA approval letter

NHS
Health Research Authority

Some materials

Coventry University
Priory Street
Coventry
CV1 5FB

Email: hra.approval@nhs.net

Some materials have

14 November 2017

Some materials have been removed due to 3rd

Letter of HRA Approval

Study title:	What are the experiences of adults with Intellectual Disability and Dysphagia? An exploratory study.
IRAS project ID:	233048
REC reference:	17/IEC08/0049
Sponsor	Coventry University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England
The sponsor should now provide a copy of this letter to all participating NHS organisations in England.
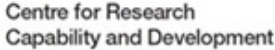
Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Page 1 of 8

110

Appendix 11: Summary of recommendations for dysphagia practice

- ❖ The physical, social and psychological consequences of having dysphagia should be addressed by dysphagia services.
- ❖ Psychology services should form part of the core MDT supporting people with dysphagia and offer 1:1 Support.
- ❖ Services to set up support networks for people with dysphagia.
- ❖ Services to provide person-centred dysphagia care;
  - o Ensure dysphagia assessments include favourite foods to prevent unnecessary food restrictions.
  - o Individual preference of using thickener should be considered and any alternatives discussed.
  - o Involve individuals in decisions regarding the use and types of mealtime prompts.
  - o Seek individual preference regarding proximity of clinicians during dysphagia assessments.
  - o When appropriate, offer the option of eating together with clinician during dysphagia assessment process.
  - o Involve individuals in decisions regarding maximising mealtime independence.
  - o Ensure dysphagia assessment findings are fed back to client.
- ❖ Services should work with community settings i.e. cafes / restaurants to advocate 'dysphagia friendly' environments.
- ❖ Services should provide individuals with advice regarding eating out with dysphagia;
  - o Suggest the individual with dysphagia sits with their back to the café / restaurant to reduce any embarrassment regarding modified food and drink.
  - o Choose foods from the menu which are the appropriate texture in their natural form e.g. mashed potato, soup
  - o Contact the café / restaurant in advance to explain individual eating / drinking requirements to reduce discussion once there.
  - o To avoid food modification taking place at the table, request for meals to be modified in the kitchen prior to serving. Information regarding target food texture could be printed on pre-prepared cards and handed to waiting staff to avoid discussion.

			Library Declaration and Deposit Agreement
Coventry University	**Doctoral College** | Centre for Research Capability and Development		

Forename: Rachael		**Family Name:** Kasch
Student ID: 6783008	**Faculty:** Faculty of Health and Life Sciences	**Award:** Mres

Thesis Title:
The Experiences of Adults with Intellectual Disability and Dysphagia: An Exploratory Study

Freedom of Information:

Freedom of Information Act 2000 (FOIA) ensures access to any information held by Coventry University, including theses, unless an exception or exceptional circumstances apply.

In the interest of scholarship, theses of the University are normally made freely available online in the Institutions Repository, immediately on deposit. You may wish to restrict access to your thesis for a period of up to three years. Reasons for restricting access to the electronic thesis should be derived from exemptions under FOIA.
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Do you wish to restrict access to thesis/submission:	No

Please note: If your thesis includes your publications in the appendix, please ensure you seek approval from the publisher first, and include their approval with this form. If they have not given approval, they will need to be removed from the version of your thesis made available in the Institutional Repository.	
If Yes please specify reason for restriction:	
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Does any organisation, other than Coventry University, have an interest in the Intellectual Property Rights to your work?	No
If Yes please specify Organisation:	
Please specify the nature of their interest:	

Signature:	Date:
R.Kasch	1/11/18

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Date of Thesis release to Library	