Relationships and Power: An exploration of the systemic factors that impact upon the lives of adults with Intellectual Disabilities in residential services.

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DECLARATION

I declare that the work contained in this thesis is my own, except where due acknowledgment has been made. No part of this thesis has, to my knowledge, been submitted for examination by any other institution.

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ABSTRACT

This research aims to explore the experiences of adults with intellectual disabilities (ID) who live in residential services, and staff, of the social processes that impact upon person-centeredness, and discover what their subjective experiences can tell us about the relational and cultural dynamics that exist in disability services in the Republic of Ireland, and their impact upon the quality of life of adults with ID who live in residential services. The study was undertaken to address the lack of research currently available on understanding the social processes that exist in disability services, from the perspective of adults with ID and staff, to explore the importance of taking a relational perspective into account in policy development and service practices, and to consider the influence of psychologists working relationally in disability services to promote person centred cultures that safeguard against abuse.

Semi-structured interviews of six adults with ID who live in residential services and six staff employed by the same disability service were conducted to collect the data and a phenomenological study using thematic analysis was applied to analyse the findings. This study revealed there are complex social and cultural processes that exist in disability services, which undermine the development of person centred cultures that are vital to underpin changes in power and power relationships between adults with ID, support staff and the disability service in the safeguarding against abuse in disability services.

The implications of this study are discussed in terms of their applicability to psychological, social care and health practices and in the development of policies that guide models of care for adults with ID who live in residential services. This research is a call to recognise that it is not enough to have a system of quality of care guided by the principles of person centeredness alone to ensure the best possible quality of life for adults with ID. Rather, consideration of the cultural and contextual factors that impact upon the relationships held by adults with ID needs to be built into the values and practices of services offered to adults with ID in the Republic of Ireland and beyond.

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DEDICATION

Fia and Emily, my girls.

My grandparents Henry and Mailo, whose love led the path to Ealing.

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LIST OF ABBREVIATIONS

APA	American Psychiatric Association
BPS	British Psychological Society
DOH	Department of Health
DOHC	Department of Health and Children
DSM-V	Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition
EASPD	European Association of Service providers for persons with disabilitites
EAP	Employee Assistance Program
HIQA	Heath Information and Quality Authority
HSE	Health Service Executive
ID	Intellectual Disability
ICD-11	International Classification of Diseases - 11
IPA	Interpretative Phenomenological Analysis
IQ	Intelligence Quaotient
NDA	National Disability Authority
NHS	National Health Service
NFNB	National Federation of National Bodies
PCP	Person centred planning
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Chapter 1. INTRODUCTION

1.1. The problem

Adults who carry the label 'Intellectual Disability' (ID) are more likely to experience abuse (see section 1.1.8 below and Appendix A for more detailed definition of abuse), and are particularly more vulnerable should they live in residential services (Beadle-Brown et al., 2010). While support in residential services for adults with ID has improved, there continues to be pockets of abusive care throughout the Republic of Ireland and the United Kingdom (UK) (British Psychological Society (BPS), 2018). Perhaps the most shocking of these examples in the Republic of Ireland was when an undercover reporter highlighted many incidents of abusive care practices at 'Aras Attracta', a residential service in county Mayo (Health Service Executive (HSE), 2016). This particular case led to a review of the service by the HSE (service provider) and a review group was established intended to improve the safety and quality of life of service users in the centre. The findings of the review group were published in the "*What matters most*" report which highlighted a number of key initiatives to inform the wider intellectual disability sector in order to prevent such abusive practices occurring again (HSE, 2016). This review highlighted that an institutionalised culture led to abusive practices developing, as a result of a model of service which promoted dependence over independence. This did not equip residents to make decisions over their lives nor did it take into account individuals potential; failing to respect the dignity and rights of individuals (HSE, 2016). The key recommendations from the report to support a change in such culture within disability services are as follows; 1) residential services should move to a rights-based social model of service delivery, 2) disability services should move from congregated settings towards community based residential services, 3) there needs to be greater emphasis within disability services of person –centred practices, 4) staff need to have a clear understanding of their role, and 5) the report identifies the need for the voices of adults with ID to be facilitated listened to and promoted (HSE, 2016). These findings correlate with those found within the literature, whereby abusive practices are more likely to develop in services where adults with ID have limited choice, control and collaboration over their lives (White et al., 2003). The findings also consider de-congregation and person-centred practices to be fundamental to transformational change within disability services. However, research has yet to show that de-congregation and person-centeredness (see section 1.6.1 below for definition) can reduce the risk of abuse and abusive practices developing in disability services (Robinson & Chenoweth, 2011). While the findings are welcome in offering recommendations towards changing organisational wide practices, what these findings do not offer is an understanding of what occurs at a relational level between adults with ID and their support staff, and what drives thinking and behaviour in disability services that leads to the development of poor and abusive care practices (Thornberry & Olson, 2005).

As will be discussed in more detail below, we know that our cultural history has associated adults with ID as objects of disgust and fear and also as objects of pity and misfortune (Hughes, 2009; 2012). This has led to adults with ID often being treated as sub-human with little regard for their emotional feelings (Richards, 2016). Such attitudes continue to pose a threat to the full inclusion of adults with ID in society, and may continue to allow for abusive practices to flourish within disability services (Sheridan & Scior, 2013; Richards, 2016; 2019). Therefore, research which aims to explore the subjective experiences of adults with ID living in residential services, from a relational perspective, will provide further insight and understanding of the cultural and contextual issues that impact upon the lives of adults with ID. This alternative perspective may assist in the development of a wider variety of psychological intervention and practice within the field.

1.2. Definition of terms

Given my own background; as a Counselling Psychologist and Psychotherapist working within a disability service, when I commenced this study I began to use terms that were regularly used by disability services and clinicians. For example; persons who use services, service users, residential care and support staff. Similarly, within the literature terms and definitions used varied considerably such as; learning disability, intellectual disability, abuse, maltreatment, group homes and community services. Given the variety of terms used and the discrepancies across definitions, to make it easier for the reader, I have set out below the terms and definitions that I will use throughout the study.

1.2.1. Intellectual Disability

'*Intellectual disability*' is a socially constructed term and its meaning and definition has been subject to much change over time (Hatton, 2012). While the term 'intellectual disability' is used in many countries including the Republic of Ireland, the term 'learning disability' is often used in the UK and 'mental retardation' or 'developmental disability' is most prevalent in the United States of America (USA) and Canada. However, the term *intellectual disability* is increasingly used internationally, which reflects the changing construct of disability and aligns itself with contemporary professional practices that focus on functional and contextual factors and is less offensive to adults with ID (Schalock, 2011). For the purposes of this study, I will use the term *'intellectual disability'* as it is the term most widely used in the Republic of Ireland and utilised by the Department of Health (DOH, 2011), the Health Service Executive (HSE, 2011) and Health Information and Quality Authority (HIQA, 2013).

1.2.2. Defining Intellectual Disability

Adults with an ID are not a homogenous group; however, in terms of diagnosis and classification there are a number of features that have gained widespread professional acceptance internationally (Keenan & Doody, 2017) these are;

1. Impairment in intelligence confirmed by both clinical assessment and an individualised, standardised intelligence test.
2. Impairment in adaptive functioning deemed to be below average relative to the general population.
3. Onset of intellectual and adaptive deficits manifest before the age of 18 years.

The types of cognitive impairment observed following clinical assessment are often categorised into four categories; mild, moderate, severe and profound. Table 1 below shows the classifications of ID in relation to an average intelligence quotient (IQ) of 100 as measured on a standardised intelligence test. Both the Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-V) (American Psychiatric Association (APA), 2013) and International Classification of Diseases -11 (ICD-11): Mental and Behavioural Disorders (World Health Organisation (WHO), 2018) agree that all three of the above criteria are necessary for a diagnosis of ID. However, both the DSM-V and ICD-11 place less emphasis on the degree of impairment (i.e. IQ score as outlined in Table 1 below) and more on how an individual's relationship with their environment can impact upon their functional ability regardless of I.Q. and stresses greater appreciation for this during the diagnostic assessment (APA, 2013).

Table 1 Levels of ID (DSM-V)

Levels of ID (DSM-V)

Level of ID	**Intelligence Quotient (IQ)**
Mild	IQ level 50-55 to 70 (approx.)
Moderate	IQ level 35-40- to 50-55
Severe	IQ level 20-25 to 35-40
Profound	IQ level below 20-25

Mental Health professionals are asked to consider a person's ability across three domains; conceptual, social and practical. This aims to ensure that the emphasis of assessment is less about the degree of impairment and more about the type of support and intervention needed to enhance the individual's ability to engage fully with their environments (APA, 2013). As professionals this updated diagnostic criteria is challenging us to consider the construct of ID. Moving away from viewing ID as a personal deficit, to now focusing on functional limitations, whereby an adult with ID can be influenced by their social context. This represents our increased understanding of the process of disability and its improvement. The WHO (2010) has endorsed this changing view of ID, and emphasises the need to understand an individual's needs by taking into account the context of environment and relationships. As a Counselling Psychologist and Psychotherapist, this informs my view on what I expect from an adult with ID and the skills and tasks that can be achieved which assist in determining the individual supports required. This is in line with the growing movement of inclusion and self-determination, whereby those with a 'disability identity' should no longer be denied certain rights or marginalised, as a result of a perceived inability to conform to societies' norms (McClimens, 2005).

1.2.3. Service User and adults with ID

The term ‘service user’ will be used interchangeably with ‘adults with ID’ throughout the study to refer to adults with ID living in community residential services, as it is the term most commonly used in practice. It is also the term that participants identified most with and felt most comfortable with being referred. Therefore, I use the term ‘service user’ specifically when referring to those adults with ID who participated in the study and will use the term ‘adults with ID’ when speaking more generally about the population.

1.2.4. Staff

Due to the nature of how disability services are currently structured within the Republic of Ireland, adults with ID have many individuals involved in their care. Most disability services have a management structure augmented by a team of multidisciplinary professionals, which often include; psychologists, psychiatrists, social workers, speech and language therapists and intellectual disability nurses. Supporting adults with ID in their day and residential services are often a team of social care staff whose primary function is to work in partnership with the individual, so that they may enjoy a good quality of life (HIQA, 2013).

‘Staff’ in this study were either; social care staff working in community residential services supporting a service user in their home, managers of a disability service or multi-disciplinary team professionals employed by the disability service.

1.2.5. Disability Service

Within the Republic of Ireland, it is considered that the obligation to provide health services for adults with ID rests with the state (Government of Ireland, 2005). Most of these services are delivered by non-profit organisations funded through arrangements made with the HSE. The services provided by the non-profit organisations include; direct provision of care (day and residential services), rehabilitative care and respite services. For the purposes of this study, I will use the term 'disability service' when referring to disability service providers.

1.2.6. Residential service

For all adults with ID who need to live in full-time residential services the model of provision, as set out by the Government (HSE, 2018), is based on person-centeredness (see section 1.6.1 below for definition). It is envisaged that all housing made available to adults with ID should be in local neighbourhoods in the community, where each adult with ID should have access to a range of individualised supports, which enable them to live as independently as possible in the home of their choice (HSE, 2011). The types of community based accommodation may include;

- Living alone
- Sharing with others without an ID
- Sharing with others with an ID (no more than four adults with ID sharing together)

For the purpose of this study, the term "residential service" will be used to refer to any of the community based accommodation options, as described above.

1.2.7. Vulnerable Adult

In 2014 the HSE launched its safeguarding policy, "*Safeguarding Vulnerable Persons at Risk of Abuse - National Policy and Procedures, for older persons or persons with a disability"* (HSE, 2014). This policy outlines a number of principles to promote the welfare of vulnerable people and safeguard them from abuse, and applies to all those who live in HSE or HSE funded services. For the purpose of this study, the definition of vulnerable adult, as outlined within this policy, is adopted as it applies to the disability service in which the study was conducted;

> A vulnerable adult is defined as "an adult who may be restricted in capacity to guard himself/herself against harm or exploitation or to report such harm or exploitation (HSE, 2014, p. 3).

1.2.8. Definition of abuse

Within the literature regarding the abuse of adults with ID, the definition of abuse is inconsistent, and is often used interchangeably with other definitions such as ‘maltreatment’. In order to provide clarity for the reader, within this study the definition of abuse used is the one which is defined in the National safeguarding policy (HSE, 2014), as it applies to all disability services in the Republic of Ireland;

> Any act, or failure to act, which results in a breach of a vulnerable person’s human rights, civil liberties, physical and mental integrity, dignity or general well-being, whether intended or through negligence, including sexual relationships or financial transactions to which the person does not or cannot validly consent, or which are deliberately exploitative. Abuse may take a variety of forms (HSE, 2014, p.8).

Furthermore, while this definition focuses specifically on acts of abuse by individuals, it is understood that abuse can also arise from inappropriate or inadequate care (HSE, 2014). Similarly, abuse in any of its forms may be perpetrated as the result of “deliberate intent, negligence or lack of insight and ignorance” (HSE, 2014, p. 8).

The following are considered as the main categories of abuse (for further detailed information regarding each type see Appendix A);

- Physical Abuse
- Sexual Abuse
- Psychological Abuse
- Financial Abuse
- Neglect and acts of omission
- Discriminatory Abuse
- Institutional Abuse

1.3. The need for improvement in the safeguarding of adults with ID from abuse.

Currently within Ireland there are over 28,000 adults with ID in receipt of day and residential service supports, with approximately 8,000 adults with ID living in full-time residential services. It is estimated that a further 2179 full-time residential places will be needed between 2018 and 2022 (Health Research Board, 2017). Often the need for residential services arises when an individual's needs are such that their family can no longer provide support at home. It is hoped when making such a decision that the services available are of good quality and safe. To ensure this, in 2013, HIQA was established as an independent authority to inspect all registered residential services. In order to be registered to operate, HIQA must certify all residential services confirming that they meet the requirements and regulations, as set out in the Health Act 2007 (Government of Ireland, 2013) and the National standards for residential services for children and adults with disabilities (HIQA, 2013). In July 2019, HIQA published a report detailing their findings following its first five years of operation. It was of concern to me to learn in this report that despite the legislation, regulations and national standards, HIQA has stated that there needs to be continued improvement in the safeguarding and safety of adults with ID who live in residential services (HIQA, 2019a).

Since the uncovering of abusive practices at Aras Attracta many reports have been documented subsequent to the inquiry. All of which have been aimed at transforming national policies, but most importantly, emphasising a need for a cultural shift demanding that within society we take a look at how we think and feel about adults with ID (Association of Chief Executives of Voluntary Organisations, 2016; Transforming Care Delivery Board, 2015; National Health Services (NHS), 2015; Royal College of Nursing, 2014; Department of Health, 2012a). Recommending a need to change our cultural perspective points to something deeper about our relationship with intellectual disability, and what is evoked in a relational context that may lead to abusive practices developing in residential services.

The history and histories of adults with ID is complex and the current models of disability (see section 1.4 below), the philosophies underpinning service provision (see section 1.4 below) and the construct of what the label of ID means (see sections 1.1.1 & 1.2.1 above) have all grown from a very particular historical and cultural context (Bungener & McCormack, 1994; BPS, 2018). It is argued by Thornberry and Olson (2005) that it is the culture of segregation that has contributed to the perception that adults with ID are vulnerable and attractive targets for abuse. Cambridge, et al. (2006, 2011c) have highlighted several issues which predict the risk of abuse in disability services including; frequent incidents of intimidation of junior staff, management failure, dehumanising regimes and not taking victim's complaints seriously. These issues suggest that within disability services certain stereotypes manifest which impact how we relate to adults with ID.

I struggle to understand how abusive practices can continue to occur within such services today, when the philosophies of care and our understanding of disability have changed so much since the nineteenth century days of institutionalisation. There is something about our relationship with adults with ID that has not changed, and it is from this position that I am motivated to know more about how adults with ID and staff experience social processes that impact upon person centred care in residential services in the Republic of Ireland, so that I may begin to understand at greater depth their experience of the complex relational system in which they exist.

Within the field of ID there is a need to support the transformation of care. I believe there is value in integrating working through a relational 'lens' to further understand and deepen our understanding of the subjective experiences of adults with ID who live in residential services, as a means of safeguarding adults with ID from poor or abusive care practices now and in the future.

Understanding the relational dynamics between adults with ID and the services charged with their care warrants exploration. On the basis that so little research exists towards understanding how adults with ID experience the realities of living in residential services, and how this is understood within the context of the service provider, the current research aims to bridge this gap.

1.4. Models of Disability

In order to conceptualise the need for change within disability services it is necessary to reflect on the history of services within the Republic of Ireland. Adults with ID were not always marginalised from society, for example; during pre-industrialisation, where the emphasis was on work rather than education, saw little difference between those who could be educated and those who could not (Brandon, 1957). Adults with ID only became a problem within industrialised society when the demand for more skilled individuals highlighted the existence of those who were 'un-educable' (Rafter, 1992). From this period, adults with ID began to be viewed from a perspective of fear, speculation and scientific inquiry (Clarke, 1986), and so began the struggle to support and include adults with ID into society (Carlson, 2010). In the nineteenth century, this fear resulted in the segregation of adults with ID from mainstream society into institutions where they remained hidden for many years (Ryan and Thomas, 1980), until the beginning of de-institutionalisation in the 1980's when the experiences and situations of adults with ID began to be examined as unacceptable (Hall, 2010).

As we progress with understanding adults with ID as deserving of equality within society, this has driven the debate of trying to determine what constitutes a good paradigm of care for this group of people. Determining how we can *look after* adults with ID has changed considerably and has largely been determined by how the social construct of disability has changed from the 1930's 'morons' to the 2000's 'active citizens'. From the 1970's onwards perspectives began to change, and an adult with ID's potential to be educated saw a shift in the kinds of facilities developed to 'contain' those who were previously deemed to be dangerous (Carlson, 2010). Although these changes have afforded adults with ID with better living conditions, increased opportunity for education and training, the question remains whether adults with ID are truly included and equally valued in society (Atherton, 2007). There are many different lenses from which to understand the place of adults with ID in society (Ryan and Thomas, 1980). The most dominate of these is the medical and the social model, both of which have implications for professional policy and practice (Buntix & Schalock, 2010). As they provide a framework to understanding the values that inform services that support adults with ID and influence how supports are provided.

1.4.1. Outline of the Medical Model

The medical model locates pathology within the individual emphasising the individuals' deficiencies rather than their abilities. Oliver (1996) calls this the personal tragedy theory, which perpetuates a culture of dependency and non-acceptance allowing no self-determination. The medical model is criticized for seeing an individual's impairment as the most important part of the person, and suggests that the person is helpless to do anything about their difficulty. The medical model sees the disability alone as the problem which demands treatment to fix in order for the person to be considered as equal, amongst other able bodied peers.

1.4.2. Outline of the Social Model

In contrast, the social model has influenced the perception of disability and impairment to one of human difference and not a deficit. The social model suggests that if people with impairment do not have their needs met by society, they are being 'disabled' by society's choices and attitudes alone. The social model calls for a conceptual shift in thinking; from seeing 'disability' as a problem, to embracing a perspective which recognises people with impairment as a minority group oppressed by society. Chappell, Goodley & Lawthorn, (2001) champion the social model as being the 'emancipatory road' which professionals need to follow. This has seen a rise in the development of systems advocating for person-centred care (see section 1.6.1 below for definition). Whereby, adults with ID are seen as equal partners in planning, monitoring and developing their own care. Such values have become fundamental to current health and social care policies in the Republic of Ireland (Department of Health & Children (DOHC), 2008; DOHC, 2009; Department of Environment, 2011; HSE, 2011; DOH, 2011; HSE, 2015). However, the social model fails to recognise the impact that disability can have upon an adult with ID. As a result, there is a concern that in focussing on the wider social attitude may risk not fully understanding the individual needs of a person.

While both models may be helpful in attempting to improve the lives of adults with ID, both may also serve to create difficulties. It is, therefore, my view that it is important to hold a more nuanced view of disability which recognises the impact society can have, but also recognises the impact impairment can have upon the personal experience of the person.

1.5. Philosophies underpinning Disability Service Provision

A brief discussion of the philosophies which underpin disability services and practice within the field of ID within the Republic of Ireland and internationally over the past 40 years (HSE, 2011) provides a context to the evolution of residential services, such as the one in this study, and current social policy in the Republic of Ireland, which leans towards person centeredness (see section 1.6.1 below for definition).

1.5.1. Brief outline of the philosophy of 'Normalisation'

The idea of 'normalisation' was initiated in the 1970's when Wolfensberger (1972) began to highlight how adults with ID have been marked apart by being symbolically stigmatised. The values inherent in 'normalisation' and 'inclusion' promote the belief that adults with ID should enjoy a quality of life and position in society which is equal to, and would be valued by the general population (Feehan & Hutton, 2003). The underlying principle of 'normalisation' adopted by policies in the Republic of Ireland is to "enable each individual with a disability to achieve his/her potential and maximum independence, including living within the community as independently as possible" (DOH, 2001, p.141). This 'new' thinking sparked a movement from segregated institutions to community-based settings. As societies have become more willing to integrate adults with ID into local communities (National Disability Authority (NDA), 2011, 2017) paradigms of care such as those influenced by 'normalisation' (Wolfensberger, 1970) have begun to shape disability services.

Within the Republic of Ireland ‘normalisation’ has had the greatest influence on how disability services have been designed, and operationally services interpreting ‘normalisation’; have relied on O’Brien & Lyle’s (1989) ‘five accomplishments model’;

1. **Community Presence:** The right to take part in community life and to live and spend leisure time with others members of the community.
2. **Relationships:** The right to experience valued relationships with non-disabled people.
3. **Choice:** The right to make choices, both big and small, in one’s life. These include choices about where and with whom to live.
4. **Competence:** The right to learn new skills and participate in meaningful activities with whatever assistance is required.
5. **Respect:** The right to be valued and not treated as a second-class citizen.

The five accomplishments represent a set of quality of life and human rights values towards which adults with ID, who are the service-users/consumers of disability service provision, should be enabled to advance (NDA, 2005).

1.5.2. Brief outline of philosophy of ‘Social Inclusion’

‘Inclusion’ is a guiding philosophy for integrating all persons with a disability into the community (Goldmeier & Herr, 1999) and developed as a logical extension of Wolfensberger’s principle of ‘normalisation’ (Simplican et al., 2015). Social inclusion for adults with ID is defined as being involved in activities, developing relationships and having a sense of belonging (Gannon & Nolan, 2005). Social inclusion is seen as a leading goal of policy and practice in care and support for adults with ID (Meininger, 2010). Social inclusion is more aligned to the social model of disability. Although normalisation and social inclusion both support the best interests of adults with ID, at heart they have different value bases and aims, which threaten their compatibility (Culham & Nind, 2008). While normalisation is challenged with seeking to ‘normalise’ an individual’s difference requiring adults with ID to conform in order to gain acceptance, it has provided an excellent starting point in which to think about how we provide services for adults with ID. Shaddock & Zilber (1991) challenge the need to think beyond normalisation when they make the comment “do we really need a separate guiding philosophy for people with disabilities or is all we need is an acknowledgement that they too have basic human and citizenship rights like everybody else?” (p. 174). This perspective has seen a further shift in how we think about disability. Inclusion, as an alternative is not just about disability, but about all aspects of diversity such as; gender, ethnicity, poverty, sexuality, and so on (Culham & Nind, 2008). Inclusion encompasses the process of increasing participation of adults with ID in mainstream communities and education. Inclusion accepts that it is the system that must adapt and not the adult with ID in order to gain entry (Mittler, 2000).

1.5.3. Brief outline of philosophy of ‘Self-Advocacy’

‘Advocacy’ is a 20th century development within disability services, and is still considered a ‘new’ concept within the disability sector in the Republic of Ireland (Woods, 2004). Advocacy is a broad concept, but the most salient point is to stand up for one’s self and/or others (Tufail & Lyon, 2007) and to enable adults with ID feel empowered as people with “power, rights and values” (Stone, 1999, p. 29).

The self-advocacy movement has, as a result, become a major vehicle for adults with ID to campaign for their rights across all aspects of society. Through self-advocacy group’s adults with ID have developed skills in speaking out for themselves, engage in meetings and seek changes within their services. Self-advocacy has provided adults with ID with an important platform to have their voices heard and in the creation of this well captured phrase, ‘*nothing about me, without me*’, has transformed adults with ID’s personal and social consciousness (Chappel, Goodley & Lawthorn, 2001). This has led the way for more collaborative relationships between adults with ID and their service providers.

1.5.4. Critique

Despite these advances and aspirations there are those who argue that the scale of such a task can be hindered unless consideration is given to changes in power relations, funding and staff training and supervision (Mansell & Beadle-Brown, 2004; Robertson et al., 2007; Cambridge, 2008). Hinshelwood (2012) adds to this argument by saying that even though we have models of care influenced by the philosophies of normalisation and social inclusion in the community; he expresses that there is no guarantee that these modern models of service delivery will eliminate the attitudes that impact negatively on the lives of adults with ID. This view has also been raised by the European Association of Service providers for Persons with Disabilities (EASPD), who too warn, that disability services need to be aware that institutionalised cultures can exist in community based residential services (EASPD, 2013). Although movements such as normalisation and social inclusion have led to improved living conditions, increased educational, training and work opportunities; they have failed to consider the experiences of adults with ID, neglecting to examine the power dynamics between adults with ID and professionals (Chappell, 1992). Self-advocacy too has been criticized leading only to small cosmetic changes while paternalistic inequalities in power relations remain in disability services (Aspis, 2002). Despite the efforts of disability services to adopt more socially inclusive environments for adults with ID, concern remains that adults with ID continue to be socially isolated and lonely, whereby staff continue to be the main providers of emotional and practical support (Forrester-Jones et al., 2006).

1.6. ‘Transforming lives’: The Irish context

Within the Republic of Ireland, from the early 1920’s, the Irish government authorised a number of Catholic orders to deliver health, social care and education on behalf of the state which marks the role played by the religious orders in “the shaping of professional care for people with an intellectual disability” in the Republic of Ireland (Sweeney, 2010, p.95). The development of such specialised centres marked the start of this specialism and saw an increase in new professions, such as ID nursing entering the field, specialising in therapies and services for adults with ID (HSE, 2011).

Influenced by what was occurring internationally, the Republic of Ireland too saw the emergence of the disability rights movement in the 1990’s, which influenced the re-direction of social policy towards community based residential services and away from institutionalised care. This time too saw the change in emphasis of service delivery, whereby adults with ID were seen to have the right to take control over their own lives and have more choices. Changing philosophies with regard to the rights of adults with ID saw a realisation that even those with severe and profound ID have the right to live a normal life. This has contributed significantly to focusing care from security, protection and uniformity, to an individualised approach which aims to put adults with ID at the centre of their care (Carnaby, 2007).

Over the last twenty years this has led to developing new types of residential services, whereby adults with ID are fully involved in planning and improving services to meet their needs. In the Republic of Ireland this has been supported by relevant policies and government legislation, such as the ‘Disability Act’ (Government of Ireland, 2005), ‘Irish Human Rights and Equality Commission Act’ (Government of Ireland, 2014), ‘A National Framework for person-centred planning in Services for persons with a Disability’ (HSE, 2018), ‘New Directions, Personal supports services for adults with disabilities’ (HSE, 2015), ‘Time to move on from congregated setting – a strategy for community inclusion’ (HSE, 2011), ‘Value for Money and Policy Review of Disability Services’ (DOH 2012b) and ‘A Vision for change’ (DOHC, 2006). All of which promote the need for adults with ID to live meaningful lives and to receive support from high quality services. These policies, as mentioned above, have culminated in a major effort to reform services for adults with ID through a government initiative entitled ‘transforming lives’, which aims to deliver a national framework based on the model of person-centred care (HSE, 2018). This framework is intended to inform and guide how person centred planning (PCP) is implemented across all services for adults with ID in the Republic of Ireland. It sets out what is good practice and how best to support individuals, teams and disability service providers to identify areas of improvement (HSE, 2018).

1.6.1. Person-centeredness

> People with disabilities…have the right to be safe, to receive person-centred, high quality services and supports and to have access to the services they need in order to maximise independence and choice and enable them to lead a fulfilling life. This basic right is fundamental to their wellbeing and healthy development (HIQA, 2013, p.3).

Person centred care is the primary focus of current Irish and international social policy in the field of ID (HSE, 2018; Department of Justice & Equality, 2017; HIQA, 2013; DOH, 2001). It is the framework that guides how best to improve the quality of life for adults with ID living in residential services, through the promotion of healthful relationships and person centred cultures within disability services (HSE, 2018). Within the national guidelines person-centeredness is defined as;

> An approach to practice established through the formation and fostering of healthful relationships between all providers, service users and others significant to them in their lives. It is underpinned by values of respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development (HSE, 2018, p. 11).

The guidance promotes the importance of healthful relationships in enabling an adult with ID to achieve maximum well-being and to flourish in all aspects of their life. It also highlights the need for cultures within disability services that continuously place the adult with ID at the very centre of their care.

Acknowledging the importance of relationships in the lives of adults with ID is a significant step in understanding that adults with ID share the same yearning, as the rest of humanity, to belong in relationship with others and/or to a place or a way of life (Hall, 2010). Clegg & Lansdall-Welfare (2010) argue that one of the major shortcomings in current policy for enhancing the quality of life for adults with ID is the failure to enhance social relationships. So it is welcome that within the Republic of Ireland there is an effort toward ensuring a coherent cultural shift across services, whereby the creation of, and enhancement of social relationships, is at the heart of what services aim to do (Clegg & Lansdall-Welfare, 2010).

Developing person centred practices is aimed through the process of person centred planning (PCP). Within the international literature there is no agreed definition of PCP; however, in the Republic of Ireland the National Disability Authority (NDA) defines PCP as:

> A way of discovering how a person wants to live their life and what is required to make that possible. The overall aim of PCP is good planning leading to positive changes in people’s lives and services (NDA, 2005, p. 12)

Those who are critical of person centeredness warn; however, that evidence supporting PCP is limited, and does not demonstrate that PCP can achieve radical transformations in the lives of adults with ID (Ratti et al., 2016). Despite the on-going emphasis of PCP, as the cornerstone of care in disability services in the Republic of Ireland, there is scant research that supports its effectiveness on the quality of life of adults with ID (Ratti et al., 2016).While some studies have shown that PCP is linked to statistically significant changes in certain ‘quality of life’ domains, research has not shown any significant impact upon enhancing inclusive social networks for adults with ID (Robertson et al., 2007; Clement & Bigby, 2010). Research undertaken by Clement & Bigby (2010) highlighted that “is it not enough to have good planning meetings that produce good personal plans - plans needs to be translated into action” (p. 109). This suggests that it is not the planning system itself that is to blame for not improving the quality of life of people with ID, but rather how the system is used (Clement & Bigby, 2010).

Richards (2019) calls for a review of how we think about the concept of person centeredness in disability services in light of the many cases of systemic abuse this century. Richards (2019) states we need a "new perspective that encapsulates people first values, which could go some way to ensuring that disabled people are no longer treated and classed as sub-human" (p. 505). Richards (2019) view is aligned with my own, whereby if disability services are to be truly person centred, we need to understand the contextual factors that limit adults with ID having full control over their lives, by focusing on the knowledge and experiences of adults with ID and challenging the cultural and institutional misconceptions of what disability means.

1.6.2. The Organisational Context and Culture

In understanding the social construct of *intellectual disability*, and how an adult with ID can be further disabled, as a result of their interaction with their environmental and social contexts, it is important to think about the organisational context and culture in which an adult with ID engages. Felce et al. (1998) suggest that service structures and processes influence service outcomes. Therefore, if organisations supporting adults with ID wish to achieve positive outcomes in the lives of those they support attention must be paid to how the service is designed and put in to practice (Clement & Bigby, 2010). Clement and Bigby (2010) in their research offer the following example; while group homes for adults with ID may be equipped with the normal range of domestic equipment, other features can undermine the "ordinary life" aspirations of adults with ID, such as the use of separate amenities for staff, which promote a workplace environment (pg. 247). If such practices are endorsed by official policy then this creates a culture of distinction, which may influence other informal practices within the service and how adults with ID are perceived (Clement & Bigby, 2010). Research by White et al., (2013) has demonstrated that there is a correlation between organisational culture and the development of informal practices that may lead to abusive practices developing.

According to the HSE (2014)-

> Culture manifests what is important, valued and accepted in an organisation. It is not easily changed nor is it susceptible to change merely by a pronouncement, command or declaration

> of a new vision. At its most basic it can be reduced to the observation the way things are done around here (p.15).

Therefore, this study argues that in order to promote protective cultures against abuse, there needs to be greater awareness and focus of the relational and systemic dynamics that exist in disability services.

1.7. Structure of this thesis

The chapters of this thesis are as follows: Chapter 2 is a review of the literature relevant to the topic under study. Chapter 3 provides a detailed description of the methodology, the methods used in this study and the data analyses process. Chapter 4 I describe the findings of this study. Chapter 5 I bring together a synthesis of the findings and discuss the themes which emerge from the findings. Chapter 6 I present the conclusion to this study.

Chapter 2. LITERATURE REVIEW

2.1. Chapter outline

The safeguarding of adults with ID from abuse is an important factor in the delivery of residential services for adults with ID in the Republic of Ireland (HSE, 2014), and significant research now exists in this area (Fyson & Patterson, 2020; Hodges & Northway, 2019; Ottman, McVilly & Maragoudaki, 2016; Cambridge et al., 2011c). The main body of this review examines what is understood within the literature about the construct of intellectual disability and how issues of power, relationships and 'otherness' can impact the lives of adults with ID, followed by discussion of the role of the psychology professional in the field of 'intellectual disability' and how our practices may assist in supporting the transformation of care needed in order to prevent incidents of abuse occurring in the future. Gaps in the literature are identified and the present study positioned in relation to the current philosophies and existing research findings; arguing for a more systemic transformation within disability services, whereby the influence of relational dynamics are considered in promoting protective cultures.

It is important within this study to avoid a disempowering perspective that paternalistically frames adults with ID as being past or future victims of abuse (Ward, 2011; Ditchman et al., 2013; Northway et al., 2013), or to over-pathologize their life experiences that suggests adults with ID are inherently vulnerable and not resilient (Goodley, 2005; McRitchie et al., 2014). However, given the increased likelihood of being exposed to adverse life experiences, and/or environmental stressors, means adults with ID are at "higher risk of having their resilience compromised and developing mental and physical health problems" (Wigham & Emerson, 2015, p. 93). With this in mind, we must as clinicians remain open to the notion that our clients with ID require an understanding of their life experiences and the potential traumatic impact of living in residential services, thereby offering a rationale for this study.

2.2. Literature search terms

Literature searches were conducted on databases Psychinfo, Psycharticles, Cinahl and Medline using terms; ‘intellectual disability’, ‘learning disability’, ‘developmental disabilities’ paired with ‘residential care’, ‘residential services’, ‘abuse’ and ‘culture’. The resulting references formed the starting point for the review, along with the following policy documents and reports;

1. A vision for change (DOHC, 2006)
2. ‘What Matters most’ Report of the Aras Attracta Swinford Review Group (HSE, 2016)
3. Time to move on from congregated settings – A strategy for community Inclusion (HSE, 2011)
4. Psychological therapies and people who have disabilities (BPS, 2016)
5. Incorporating attachment theory into practice: Clinical practice guideline for Clinical Psychologists working with people who have Intellectual Disabilities (BPS, 2017)
6. Working relationally with Intellectual Disabilities (BPS, 2018)
7. Guidance on a Human Rights-based approach in Health and Social Care Services (HIQA, 2019b)

In addition to the above keyword searches, identified academic literature references and bibliography lists were searched for further books and journal articles.

Within the field of ID there is a need to support the transformation of care. I believe there is value in integrating working through a relational ‘lens’ to further understand and deepen our understanding of the subjective experiences of adults with ID who live in residential services, as a means of safeguarding adults with ID from poor or abusive care practices now and in the future.

Understanding the relational dynamics between adults with ID and the services charged with their care warrants exploration. On the basis that so little research exists towards understanding how adults with ID experience the realities of living in residential services, and how this is understood within the context of the service provider, the current research aims to bridge this gap.

2.3. Current strategies for prevention of abuse in disability services

While in the past the potential for abuse to occur, particularly the sexual abuse of children, psychiatric patients and adults with ID, has been met with secrecy and denial (Cambridge, et al., 2011b; Lab & Moore, 2005). More recently such discoveries have not been ignored and have led to investigations, media scrutiny and public outcry (Fyson, Kitson & Corbett, 2004). While the outcomes of inquiries have led to many striking similarities regarding the culture of abuse that exists within such settings, such as dehumanising regimes and lack of staff experience and training (Cambridge et al., 2006). Robinson & Chenoweth (2011) argue whether the gravity of abuse prevalence of adults with ID living in residential services is being taken into consideration in a meaningful way. They question if disability services are responding to incidents of abuse out of anxiety and implementing systems that prioritise protecting their own practice from liability, more so than learning how best to support adults with ID who live in such services (Robinson & Chenoweth, 2011).

Within the Republic of Ireland, efforts to reduce the risk of abuse of adults with ID living in residential services and improve quality of life outcomes, have been guided by a number of policy documents and reports such as; A vision for change (DOH, 2006), '*What Matters Most: Aras Attracta Report'* (HSE, 2016), Time to move on from congregated settings – A strategy for community inclusion (HSE, 2011) and Guidance on a Human Rights-based approach in Health and Social Care Services (HIQA, 2019b). These documents all offer guidance towards how to improve quality of life outcomes and improve service cultures, to reduce the risk of abuse of adults with ID living in residential services, through de-congregation and promoting cultures of person-centeredness. However, Robinson & Chenoweth (2011) in a review of international literature show that dominant policy and practice approaches, such as de-congregation and person-centeredness, do not give adequate consideration to the prevention and protection of adults with ID from abuse. They suggest that managerial, compliance-based systems may be deflecting attention from recognising and responding more effectively to abuse and neglect at individual, systemic and structural levels. Richards (2019) calls for a review of how we think about the concept of person centeredness in disability services in light of the many cases of systemic abuse this century. Richards (2019) states we need a “new perspective that encapsulates people first values, which could go some way to ensuring that disabled people are no longer treated and classed as sub-human” (p. 505). Richards (2019) view is aligned with my own, whereby if disability services are to be truly person centred, we need to understand the contextual factors that limit adults with ID having full control over their lives, by focusing on the knowledge and experiences of adults with ID and challenging the cultural and institutional misconceptions of what disability means.

Robinson & Chenoweth (2011) highlight the focus of disability service systems is on resolving individual instances of abuse without systemic recognition and response to patterns and trends of abuse and neglect. Similarly, Fyson & Patterson (2020) understand abuse of adults with ID living in residential services as a set of relational dynamics which can create and sustain either positive or abusive institutional cultures. However, the literature has not paid any attention to these dynamics as a protective factor against abuse. Fyson & Patterson (2020) explored staff understanding of abuse and poor practice in residential services for adults with ID and highlighted that staff struggled to define either ‘abuse’ or ‘poor practice’. Most notably staff did not consider a relational perspective in their understanding of abuse suggesting that not enough attention is paid to the impact of cultural and relational dynamics within disability services in the safeguarding against abuse. Instead, the dominant focus within the safeguarding literature (Mandeville & Hanson, 2000; Marsland, Oakes & White, 2007; Robinson & Chenoweth, 2011; 2012) is that disability services need to develop strategies that focus on changing cultures and practices that promote “human-rights, quality of life and safeguarding” (Araten-Bergman, Bigby & Ritchie, 2017, p. 33). Within national policy (HSE, 2018; HSE, 2014) person centred care and the move to community living are seen as the cornerstone to cultural change within disability services. As outlined within the

‘National Framework for person-centred planning in services for persons with a disability’ (HSE, 2018), it is hoped that such cultural changes will allow for adults with ID living in residential services to benefit from having greater choice and power over their lives. The concern with regard to such policies is that they tend to focus on “managerial compliance to procedures and paperwork with little attention paid to direct observation or evaluation of care practices” (Araten-Bergman, Bigby & Ritchie, 2017, p.19). In order to establish the effectiveness of abuse prevention strategies there is a need to conduct rigorous evaluation (Robinson & Chenoweth, 2011, 2012).

Araten-Bergman, Bigby & Ritchie (2017) conducted a systematic scoping review of Australian and International literature of abuse prevention strategies. Only 6 papers met the criteria for inclusion in the review highlighting the limited research within the field. Three of the studies were designed to prevent sexual abuse and three broadly addressed other forms of violence and abuse. This review demonstrates the limited evidence about the effectiveness of programs to prevent abuse against adults with ID living in residential services. Of those evaluated they included a small number of participants and did not address the impact of the prevention programs over time. Moreover, the prevention strategies only targeted the individual level, whereby the assumption was that adults with ID living in residential services can be taught skills to aid them in preventing and protecting themselves from abuse. However, none of the studies evaluated the effectiveness in reducing the prevalence of abuse. None addressed the wider context of the systemic or cultural dimensions within the adult’s service that may have contributed to abusive practices developing. The studies also did not include adults with ID with severe or profound ID or with communication difficulties. This is likely due to the fact that the protection programs delivered and skills assessments demanded verbal ability (Doughty & Kane, 2010). Therefore, the kinds of intervention strategies evaluated to date are not appropriate for those who are most at risk of abuse.

What these findings suggest is that the focus in current strategies for prevention of abuse attempt to address the more practical easily implemented approaches such as training and education (Doughty

& Kane, 2010) rather than addressing the more difficult issues to address such as what lies at the root of why adults with ID are more likely to experience abuse when living in residential services. In considering this, I next address how the construct of ‘intellectual disability’ has likely contributed to the perception that adults with ID are vulnerable and easy targets for abuse (Thornberry & Olson, 2005).

2.4. Barriers to being

As outlined within Chapter One (see sections 1.2, 1.4 & 1.5) the construct of what the label ‘intellectual disability’ means has grown from a very particular historical and cultural context (Bungener & McCormack, 1994; BPS, 2018). I believe that the culture of segregating adults with ID in long-stay institutions, as seen since the early nineteenth century, has undoubtedly contributed to the perception that adults with ID are vulnerable and easy targets for abuse (Thornberry & Olson, 2005). This tension around how we view and understand adults with ID has also impacted the frequent changing of terms used to identify those who have a diagnosed ‘intellectual disability’. Valerie Sinason writes at length about the treadmill of changing terms that people labelled with an ‘intellectual disability’ have had to endure (Sinason, 2010). She provides a psychodynamic perspective highlighting the process of euphemism whereby it is in society’s discomfort and disturbance with the existence of ‘intellectual disability’ that has resulted in words such as ‘idiot’, ‘moron’, ‘handicap’ becoming euphemisms “because of the painfulness of the subject” (Sinason, 2010, p.35). Sinason (2010) highlights that it is not that one term is better than the other rather it is in our relationship with people that abuse lies and as such the on-going changing terms regarding the label ‘intellectual disability’ demonstrates the anxiety that disability evokes in society and our struggle to understand the meaning of disability. Literature on the labelling of adults with ID reflects their position in society at different points in time (Oliver, 1996; Ryan & Thomas, 1980). Terms used include; 'Feebleminded', 'Backward', 'Idiot', 'Moron', 'Mental Handicap', 'Mental Sub Normality' and 'Mentally Retarded'. According to Sinason (2000) “all the terms are struggling with how to name a difference, a difference that has not been chosen and is not wished for by the parents, the child or society" (p.187). The reframing of 'intellectual disability' was advocated for by adults with ID, and better reflects how adults with ID choose to be represented and how current professional practices centre more around functional behaviours and contextual factors (Luckasson & Schalock, 2013; Schalock & Luckasson, 2013; Schalock, Luckasson & Shogren, 2007). However, despite the effort to develop a term that better reflects the changing understanding of 'intellectual disability', adults with ID continue to experience a stigma associated with having the label (Dagnan & Waring, 2004; Ditchman et al., 2013). It is suggested by Caldwell (2011), Charlton (1998) and McClimens & Taylor (2003) that a disability hierarchy exists, both within mainstream society and within the disability community, which places adults with ID at the bottom. This further creates, and reinforces, stigma and oppression for this group of people (Spassiani & Friedman 2014). According to Charlton (1998) "people with physical and visual disabilities have greater political, social and economic opportunities and support system" (p.97), thus further marginalising adults with ID within the disability community. As reflected in the changing terms labelling 'intellectual disability', such as 'moron', 'retard' and 'idiot', in mainstream society such words are commonly used to denote 'stupidity' in everyday conversation. Regardless of intention, the use of such words reinforces a hierarchy of intelligence, which further position adults with ID as 'less than'.

2.4.1. Stigma

Research by Finlay and Lyons (2001) found that adults with ID did not identify with nor refer themselves by this label. In choosing to not identify with a certain 'label' can be seen as part of what Goffman (1963) called stigma. People living with an 'intellectual disability' have to face many negative assumptions and prejudices by others, which causes a tension between a person's assumed identity and their 'real' identity (Rix, 2006). Sinason (2006) refers to this as a 'secondary handicap' whereby some aspects of an individual's primary impairment may become exasperated as a psychological defence against the internal disturbance caused by stigma. This thinking is influenced by Freud's original description of secondary gain (1901) and Winnicott's description of the 'false self' (Winnicott, 1965). Which conceptualise that as an adult with ID becomes aware of their differences from others, either by their own developing realisation or from the reactions they experience from others can lead to a defensive secondary handicap, as a means of coping with their socially constructed identity (Jones, Harrison & Ball, 2008). The label 'intellectual disability' is so negatively loaded it is understandable why an adult with ID may choose to distance themselves from it (Kittelsaa, 2013). However, Dorozenko, Roberts & Bishop (2015a) caution that this constructed assumption of denial of identity, as a psychological defence, assumes the centrality of 'intellectual disability' in the lives of those living with the label. Dorozenko, Roberts & Bishop (2015a) suggest that society tends to pathologize the identities of people with ID (Susman, 1994) and the label can conceal a vast amount of human experience and many alternate identities (Kittelsaa, 2013).

Dorozenko, Roberts & Bishop (2015a) sought to explore the social construction of 'intellectual disability' further by exploring the identities and social roles of adults with ID. Their study included 18 adults with ID as co-researchers. The findings suggest that 'intellectual disability' was not important to participants. Instead their relationships, their support services, leisure and recreation activities and work emerged as being the central aspects of their lives (Dorozenko, Roberts & Bishop, 2015a). In contrast with the adults with ID sense of identity the study highlighted a number of worldviews which constructed the participants as "different, incompetent and not quite human" (Dorozenko, Roberts & Bishop, 2015a, p. 1345). This assumption of incompetence limits the likelihood of adults with ID being seen as 'normal' and functional 'human beings' capable of living an ordinary life (Goodley, 2001). This reflects a similar view to Vail (1966) who warned that once adults with ID are viewed as not quite human, the obligation to treat them humanely is moderated (Dorenzenko, Roberts & Bishop, 2015b). This study demonstrates how other people's construct of ‘intellectual disability’ has a greater bearing on how the lives of adults with ID may be limited or denied, rather than the identity that adults with ID hold of themselves. There is a tendency in disability research to orientate to the pathological and see maladaptive behaviours rather than seeing the creative, resilient or ordinary lives of adults with ID (Nunkoosing, 2019; Dorozenko, Roberts & Bishop, 2015a; Goodley & Rapley, 2001).

This is particularly evident in the research regarding adults with ID who present with ‘challenging behaviour’. There is very little research which addresses how ‘challenging behaviour’ may be a rational response to stigma, institutionalised care or as a result of an issue located within the relational system in which a person may live (Nunkoosing, 2019; Hayden-Laurelut & Nunkoosing, 2010). Hayden-Laurelut & Nunkoosing (2010) demonstrate in their paper that there can be a tendency within the systems that support adults with ID to see problems as existing within the person caused by their ‘intellectual disability’ and not as a symptom of difficulties within the relational system. Hayden-Laurelut & Nunkoosing (2010) highlight how the predominant culture toward devaluing adults with ID can make it difficult to reimagine what gets labelled as ‘challenging behaviour’. According to Wigham & Emerson (2015) the label of challenging behaviour is stigmatising and may impact upon quality of life, mental and physical health and relationships for adults with ID. Where behaviours of concern are framed as problematic or challenging, a person with ID is at risk of being seen only as a perpetrator and not as having been a victim of past trauma for example, and so they may experience support that is more punitive than therapeutic through the use of seclusion, restraints, moved to other placements and medication (Wigham & Emerson, 2015).

This reflects the power-knowledge discourse of medicine and psychology that can legitimise our knowledge and thinking around intellectual disability (Nunkoosing, 2019). The work of Foucault (1978,1979) is helpful here in understanding how meanings can get attached to how knowledge is constructed which then become the actions that adults with ID are subjected to (Nunkoosing, 2019).

In particular, the dominant representation of adults with ID as dependant and vulnerable (Wolfensberger, 2000), justifies their surveillance and placement within care systems (Nunkoosing, 2019). Goffman (1990) raised concern about how explanations derived from professional knowledge-power can support service systems invent explanations to make a person in need of support and subject to surveillance. In this regard adults with ID are subject to being portrayed as victims or as threats to society (Nunkoosing, 2019). Nunkoosing (2019) states that "the problem of the disablement of men and women who experience learning difficulties is often located in the services, the professional and lay employees of the learning disability industry…and has its origin in our attitude, our lack of hopefulness about the outcome of our support" (pg. 30). The challenge here is that people with ID are made 'other' and are devalued.

This process of dehumanisation is manifested in the exercising of control and power over adults with ID and the limiting of opportunities for adults with ID to develop social networks, employment, independent living, getting married or having children (Chapell, Goodley, & Lawthom, 2001; Dorenzenko, Roberts & Bishop, 2015b). It is argued by Beart, Hardy & Buchan (2005), that the effects of being labelled with an ID become even more oppressive by the power dynamics that exist within the relationships adults with ID hold with others; particularly when adults with ID have to struggle between their own desires and the desires of others (Spassiani & Friedman, 2014).

It is important therefore, as professionals working with adults with ID that we are aware of the presence and influence of stigmatising adults with ID and how discrediting narratives can discount the narratives of the men and women we are paid to support (Nunkoosing, 2019).

2.4.2 'Othering' of adults with ID in disability services

In understanding the social construct of 'intellectual disability', and how an adult with ID can be further disabled, as a result of their interaction with their environmental and social contexts, it is important to think about the organisational context and culture in which an adult with ID engages. Felce et al. (1998) suggest that service structures and processes influence service outcomes. Therefore, if organisations supporting adults with ID wish to achieve positive outcomes in the lives of those they support attention must be paid to how the service is designed and put in to practice (Clement & Bigby, 2010). Clement and Bigby (2010) in their research offer the following example; while group homes for adults with ID may be equipped with the normal range of domestic equipment, other features can undermine the "ordinary life" aspirations of adults with ID, such as the use of separate amenities for staff, which promote a workplace environment (pg. 247). If such practices are endorsed by official policy then this creates a culture of distinction, which may influence other informal practices within the service and how adults with ID are perceived as 'other' (Clement & Bigby, 2010).

The 'othering' of adults with ID who live in disability services has been further reflected in the literature, which has attempted to understand why adults with ID are more vulnerable to harm, exploitation and abuse within the very settings that are charged with their care (White, et al., 2003). For example, in Australia, Bigby, et al. (2012) conducted a secondary analysis of a large data set from an ethnographic study of five under-performing group homes in order to conceptualize the potential dimensions of culture that exist in services that are unable to fully meet the needs of service users. The findings outlined the following five dimensions of culture; 1) alignment of power-holders values, 2) regard for residents, 3) perceived purpose, 4) working practices and 5) orientation to change and ideas. The study observed the impact of the culture upon adults with ID in terms of their observed lack of engagement, community participation and personhood. The study also sought to draw comparisons with institutional features suggesting a stronger correspondence between institutional staff practices and the group home dimension 'regard for residents', whereby staff reflected in their language a sense of their 'otherness' (Bigby et al., 2012). Confirming the potential identified by others for institutional features informed by the historical medical model to exist in residential services (Landesman, 1988; Mansell & Beadle-Brown, 2010).

The abuse of adults with ID who live in residential services occurs within a specific cultural and environmental context (Robinson, 2013). There have been many variables identified within the research by Bigby et al., (2012), Felce, Lowe & Jones, (2002), Hastings, Remington & Hatton, (1995) and following reviews of major inquires, as to why abuse is likely to occur in residential services (DOH, 2012; HSE, 2016). Of these, organisational culture and the imbalance of power which positions adults with ID as ‘other’ has been the most commonly identified risk factor of abuse in such settings (Bigby et al., 2012; Clement & Bigby, 2010). Research by White et al., (2013) has demonstrated that there is a correlation between organisational culture and the development of informal practices that may lead to abusive practices developing. White et al. (2003), found the following significant factors to enable abusive practices to develop; 1) skills and attitudes of managers, 2) skills, attitudes and values of frontline staff, 3) service design, and 4) the physical quality of accommodation. Similarly, Cambridge et al. (2006) identified the following issues as pertinent cultural dimensions in the context of abuse occurring in ID services; 1) frequent intimidation of staff, 2) management failure, 3) dehumanising regimes, 4) failing to take complaints seriously, 5) failure to inspect services, 6) service isolation, and 7) failure to implement acceptable policies, guidelines, training and supervision. Rees & Manthorpe (2010) suggested that a lack of interaction between management and frontline staff was associated with poor professional support and supervision, which may enable abusive practices and cultures to develop.

Other cultural indicators that have been identified within the research which impact upon quality for services for adults with ID include; staff working in isolation (Cambridge, 1998), staff stress (Hatton et al., 2001) a lack of service model based on person centred care (Moore, 2001), and a lack of valuing the relationships between care staff and adults with ID living in residential services (Gray-Stanley & Murramatsu, 2011; Moore, 2001). Further research by Cambridge (1998), seeking to understand the risk factors rooted within the system structures surrounding adults with ID, have identified that staff who have engaged in abusive practices often lack training and experience.

A further study in Australia, by Bigby & Beadle-Brown (2016b), sought to build on the cultural dimensions of under-performing group homes, by analysing the culture in better performing homes. In contrast, the culture in these homes were characterised as “coherent, respectful and enabling for residents and motivating for staff” (p.316). In particular, how service users were regarded in better performing homes was striking in comparison, whereby staff attributed humanness to the resident’s differences, differences were not devalued (Bigby & Beadle-Brown, 2016).

These studies highlight how issues of difference, power and control and staff regard for residents can have a significant impact upon resident’s quality of life, and may contribute to enabling climates of abuse to develop. Furthermore, this research highlights that in order for there to be transformative change within disability services, developing awareness and understanding of the social processes that exist, such as dehumanisation, within disability services is crucial.

Devaluing adults with ID is not reflective of the social model of disability (see section 1.4.2) or frameworks of care such as person centeredness (see section 1.6.1). The aim of deinstitutionalisation and person centeredness is to ensure that adults with ID are treated as equal citizens (Nirje, 1969; Wolfensberger, 1972) and to be included fully in society and live a ‘normal’ life (Bredewold, Hermus & Trappenburg, 2020). However, research by Hutchinson & Kroese (2015) who undertook a systematic review of empirical research to explore the possible causal and risk factors linked to abuse and neglect of adults with ID living in residential services confirmed that the causal links associated with abuse were correlated with both; cultural or organisational factors, and factors at an individual or interpersonal level. Highlighting that where incidents of abuse have occurred adults with ID have been dehumanised, devalued and othered. Despite the progress towards de-institutionalisation and person-centred models of care there is concern that disablist attitudes exist in some community based service systems (Landesman, 1988; Mansell & Beadle-Brown, 2010).

While the social model of disability has played a significant role in improving the lives of many people living with impairment there is concern that this model privileges some more than others (Reeve, 2019). While there have been improvements in removing structural barriers e.g. access to buildings, the social model has not had a significant impact upon the socially constructed barriers that exist, which can impair those living with an intellectual disability full participation in society and also impact negatively upon their psycho-emotional well-being (Thomas, 2004; Reeve, 2019). While the social model of disability does not deny the reality of internal oppression and its psycho-emotional effects, it is argued by Reeve (2019) that the removal of social prejudices about disability have been overshadowed by the more easily challenged and changed material and structural barriers.

Similarly, within the literature regarding how to protect adult with ID from abuse and impact upon cultural change the focus has tended towards addressing the more practical aspects of education, training and altering frameworks of care and moving people out into the community (Reeve, 2019) rather than addressing the presence of disabling attitudes and prejudices which construct adults with ID who use disability services as ‘other’ or ‘less than’ (Bigby et al., 2012). Such oppressive actions can have the same cumulative effect as other experiences of trauma however “sometimes ‘diagnostic overshadowing’ prevents health professionals from seeing psychological distress such as self-harming for what it is – an understandable response to trauma, harassment, abuse – rather than being assumed as a ‘natural’ part of someone’s impairment” (Atkinson et al., 2014, cited in Reeve, 2019, p. 46).

It is further argued by Reeve (2019) that it is much harder to challenge the roots of prejudice because the solutions rely on changes at a structural and cultural level however that should not stop us as professionals working within the field to recognise such negative attitudes and prejudices exist at the level of the interpersonal. Therefore, our relationships with adults with ID are significant and we must not lose sight that adults with ID are real people with the same psychological reality as everyone else (Murray, 2006). According to Reeve (2019) holding this perspective as professionals will go a long way "towards facilitating an *enabling* rather than *disabling* relationship between professionals and person with intellectual disabilities" (p. 47).

2.5. The role of psychology in the field of intellectual disability

Many of the inquiries into abuse in care settings for adults with ID this century suggest that an institutionalised culture existed within the settings which dehumanised adults with ID. This positioning of adults with ID as something 'other' raises concern about how some individuals may be denied their humanity. Though psychology can play an important role in the lives of children and adults with ID particularly with regard to determining categories for diagnosis and shaping treatment, 'intellectual disability' has been a largely neglected topic of inquiry within the discipline of psychology as a whole (Ilyes, 2020). Counselling psychology in particular has been largely silent on the topic and as a profession Counselling psychologists are in the minority in this area of practice (BPS, 2018). However, there is growing recognition of the contribution that the practice of counselling psychology can make in the lives of adults with ID and the systems that support them particularly with regard to working relationally (BPS, 2018).

However, a gap within the literature is how the field of psychology influences the construct of 'intellectual disability' (Ilyes, 2020). Ilyes (2020) highlights that the field of psychology plays a powerful role in the lives of adults with ID by the way in which it defines and describes capacity, categories of disability and treatment. According to Ilyes (2020) "the terms as largely defined by the field of psychology can result in the denial of people's humanity" (pg. 2). Ilyes (2020) provides an example of this through the sharing of a court case where the question arose whether a black man labelled with an 'intellectual disability' could consent to a sexual and romantic relationship with a white non-labelled woman. According to Ilyes (2020) as a result of the construct of ‘intellectual disability’ this gentleman was erased from participating in the court case and was not asked about his lived experience instead the expert opinions of professionals who relied on psychological assessments and IQ tests were sought. As a result of which this case concluded that the gentleman was a victim of a criminal and abusive offence and not as a man capable of love and a consensual relationship. This example highlights how the continuance of professional power-knowledge within the psychological profession results in actions that can have potentially negative consequences (Ilyes, 2020; Teo, 2010). What occurred in that American courtroom in 2015 could be argued is mirrored within the systems of disability services that dehumanise and silence adults with ID as a result of dominant cultural assumptions based on professional power-knowledge (Ilyes, 2020). It is important therefore as professions working within the field of intellectual disability that we examine the assumptions that underline our work and make explicit that which is denying adults with ID their full human rights.

2.6. Conclusion

The status of ‘intellectually disabled’ is one that is socially and culturally acquired (Nunkoosing, 2019) and often determined by a “host of psychological, educational and medical professionals” (Nunkoosing, 2019, p. 26). One does not become ‘intellectually disabled’ by oneself and how we construct our knowledge about ‘intellectual disability’, talk and write about it contributes to the narrative of our work and relationships with those who carry this label (Nunkoosing, 2019). It is important therefore, that we listen to the voices of those who experience intellectual disability and allow for their experiences to inform and improve the services and our relationships with those people we are meant to serve (Nunkoosing, 2019).

What has emerged from this literature review is the relationship between direct care staff and people with intellectual disabilities and the dimensions of cultures which emerge, as a result of this relationship, can impact on quality of care and may increase the vulnerability of adults with ID to abuse within residential services (Bigby et al. 2012; Bigby & Beadle-Brown, 2016a, 2016b). The research also indicates that the focus of prevention strategies at the individual level are not appropriate for those with more complex needs and who are more at risk of abuse.

What is apparent within the literature is that there is some understanding of the systemic nature of care-giving in residential services, but a failure to acknowledge that in enhancing quality of care for adults with ID services must acknowledge the dimensions of culture that exist, which disfavour the kind of human to human contact that promotes quality of life (Schuengel et al., 2010). In order to reduce the prevalence of abuse in the lives of adults with ID living in residential services, research and interventions need to evolve from the "response-to-risk approach and to a broader framework encompassing individuals safety as part of their quality of life" (Araten-Bergman, Bigby & Ritchie, 2017, p. 32).

As a practising Counselling Psychologist and Psychotherapist in the field of ID, I hoped this exploration of the subjective experiences of adults with ID who live in residential services and their support staff would yield valuable insights, both for myself and for other psychologists and social care practitioners. In order to improve our understanding and supports of adults with ID who live in residential services and stimulate thought with regard to the reformulation of care within disability services in the Republic of Ireland.

Therefore, the aim of this study is to explore the experiences of adults with ID who live in residential services, and their support staff, of social processes that impact upon person-centeredness in residential services, and discover what their subjective experiences can tell us about the relational and cultural dynamics that exist in disability services, and their impact upon the quality of life of adults with ID who live in residential services.

Research objectives:

1. Explore the nature of the relationship between adults with ID and staff.
2. Identify factors that impact upon person-centeredness in residential services.

3. Explore the nature of organisational culture in disability services and its impact upon the quality of life of adults with ID who live in residential services.

Chapter 3. METHODOLOGY

3.1. Chapter Outline

The aim of this study is to explore the experiences of adults with ID who live in residential services, and their support staff, of social processes that impact upon person-centeredness in residential services and discover what their subjective experiences can tell us about; 1) the relational and cultural dynamics that exist in disability services, and 2) their impact upon the quality of life of adults with ID who live in residential services. Taking into account the aim of the study and the research objectives identified (see section 2.6 above), the current chapter discusses the chosen qualitative research design, outlining how a phenomenological study using thematic analysis was selected as an appropriate methodology to explore the aim and objectives of this study. It outlines participant recruitment and data collection, an examination of the ethical considerations, provides an overview of the approach taken to analyse the data and concludes with how rigour was ensured throughout the study.

3.2. Philosophical stance

Fundamental to my practise as a Counselling Psychologist and Psychotherapist is that I believe there is no ‘one truth’. Rather, I think about human nature and experience as being constructed by multiple perspectives, influenced by complex interactions with social, cultural, religious and political contexts. Understanding context is an important consideration in my work and enables me to appreciate the individuality and uniqueness of all people. I believe that as humans, we cannot be fully understood, without thinking about the multiplicity of factors that interweave and influence our ‘Being-in-the-world’; this is my understanding of Heidegger’s (1978) concept of “Dasein”, whereby we stand co-created and inseparable from our relationships. This guides my belief that as humans we are relational beings and our reality, as we know it, is constructed intersubjectively.

Therefore, I have approached my study from a social constructionist perspective (Klostermann & Forstadt, 2016), whereby I take the position that multiple realities and perspectives exist and where it is possible to co-create alternative stories (Hayden-Laurelut & Jones, 2019). The notion that knowledge and meaning is developed in coordination with others, rather than separately within each individual (Leeds-Hurwitz, 2009), aligns with my ethos as a Counselling Psychologist and Psychotherapist of the co-constructed relationship. Taking this approach means that there is scope to acknowledge the historical, cultural and social impact upon the lives of adults with ID. This stance aligns with the philosophy of phenomenology, as outlined by Husserl (1965), which considers our reality to be inseparable from our interactions with the physical world (people, places, things) and our interpretations of it. This forms the starting point for how I come to understand lived experiences, and forms the ontological and epistemological foundation of this study.

3.3. Choice of methodology

Throughout my training in Counselling Psychology and Integrative Psychotherapy, I have sought to conduct research which included adults with ID. Working throughout my career with such a marginalised group, it was really important to me to gain greater insight into the experiences of adults with ID living in community residential services, their relationship with staff and the impact that this has on their quality of life. Given the emphasis of this study was to understand the lived experiences of adults with ID who live in residential services, and staff, of the social processes that impact upon person-centeredness in residential services, my aim was to gain insight into and grasp the essence of what all participants had in common (Creswell, 2013). Therefore, a qualitative approach was considered as the most appropriate design for this study (McLeod, 2003). Qualitative methodologies have gained respect within the social sciences through the past two decades (Hammersley, 2008) and are considered relevant within the health professions (Neubauer, Witkop & Varpio, 2019). During my journey through my doctoral studies, I was particularly drawn to conduct an ethnographic study, as I was curious about the cultural dimensions that exist within disability services. I sought to gain an in-depth understanding of the participant's individual experiences, while also observing the interaction that adults with ID and staff had with each other and the disability service. In order to gain a deeper understanding of the context of how supports are both offered and experienced by adults with ID residing in a disability service. My training as a Counselling Psychologist and Psychotherapist leads me to believe that in understanding the psycho-emotional needs of adults with ID, through the quality of relationships that they experience, will lead to better outcomes in terms of quality of care and quality of life, and so, an ethnographic methodology seemed a good fit in order to observe how adults with ID and staff interact within disability services.

Unfortunately, after 6 months of trying to establish contact with a number of residential services, it became apparent that I would be unsuccessful in obtaining consent to engage in an ethnographic study within a disability service. As many potential participants expressed great discomfort in having a stranger observe them in their homes. Having exhausted all options within the service, and given the time constraints I was under to complete my study in a given timeframe, I did not think it was feasible to approach another disability service, as ethnographic studies take up so much time during the data collection period.

Throughout this process I became aware that both adults with ID and staff expressed a great deal of interest in participating in my study and spoke to me about how they were interested in research that could help toward changing organisational culture. Having the support of the disability service on board and the interest of a number of service users and staff, with regard to my project, I chose to change my research design to accommodate both the experiences of adults with ID and staff within the disability service, giving me an insight into how both parties experienced social processes that impact upon person-centeredness within the disability service through semi-structured interviews. Changing my research design and removing direct observations made a considerable difference to how my research study made adults with ID and staff feel, and made participation more meaningful when only the subjective experience of participants was sought.

3.3.1. Phenomenology

I was drawn towards a phenomenological study as it seemed the most fitting for my research into individual experiences. Phenomenology tries to "capture as closely as possible the way in which a phenomena is experienced within the context in which the experiences takes place" (Giorgi & Giorgi, 2003, p. 27). I first considered Interpretative Phenomenological Analysis (IPA) as it allows for detailed exploration of how individuals make sense of their experiences (Brocki & Wearden, 2005). IPA is considered as a "distinctive approach in conducting qualitative research in psychology" (Brocki & Wearden, 2006, p. 87) making it ideally suited to studying how participants make sense of their experiences living and working in a disability service. However, as IPA develops codes and themes for each data item, in order to focus on the unique characteristics of each participant, it was felt that IPA would have been better suited if I was only using one homogenous set (e.g. adults with ID).

I also considered Grounded Theory as a methodological approach. However, the focus of the study was not to develop a theory, but rather to explore at depth the individual experiences of participants. In order for the data to emerge via patterns and themes, allowing for a depth of exploration of individual experience across both participant groups, which other qualitative methods such as Grounded Theory (Glaser & Strauss, 1967) and IPA could not match.

Therefore, as I was seeking to develop themes and patterns across two groups of participants (both a group of adults with ID and a group of staff) a phenomenological study using thematic analysis was considered the best fit with my study's objectives.

3.3.2. A phenomenological study using thematic analysis

A phenomenological study using thematic analysis offers a focused systematic and flexible approach to data collection and analysis (Sundler et al., 2019), and is particularly suited to studying human processes, particularly with regard to this study, as there are few studies which seek to explore the experiences of adults with ID and staff and how they talk about it. Therefore, this research is exploratory and sought to obtain rich data. Using thematic analysis allows for links to be made both across groups and within groups, finding themes and patterns (Braun & Clarke, 2006; 2013; 2019) without being constrained by any one epistemological position. Being positioned independent of theory and epistemology allowed for greater flexibility in which to approach and understand the data from a social constructionist position (Braun & Clarke, 2006). In order to do this, I have followed Braun & Clarke’s (2006) steps (as outlined in Table Four below) in using thematic analysis to arrive at patterns in the data, and to explore the data and how participants are talked into being and positioned.

3.3.3. Position of researcher

There are many factors which will influence the ‘lens’ in which I engage in this research and analyse the data; from my own history, culture, work experiences and educational understanding of the field of ID, as well as my own bias that I bring to the research study (Dwyer & Buckle, 2009). As I manage this reality it is important I am transparent in how I construct my understanding of ‘disability’. In taking a relational and contextual philosophical stance that positions the person as inextricably linked to their history, culture and social systems, I take the view that difference and restriction is socially created (Morris, 1991). I rely therefore, on the social-relational model of disability (Thomas, 2004) in how I come to understand how social-relational processes may undermine the emotional and psychological well-being of adults with ID (Haydon-Laurelut, 2009). The social-relational model is borne from the social model of disability, which views ‘disability’ as the social exclusion of people on the grounds of impairment (Thomas, 2004).

Furthermore, given how close I am to the research topic, and the risk of my ‘pre-supposition’ regarding what may emerge from the data (McLeod, 2003), I became aware of the need to develop what Braun and Clarke (2013) refer to as, *qualitative sensibility*. This involved identifying my own assumptions in entering into the research process and engaging in reflexivity to critically reflect on my own process relative to the research. Reflexivity refers to the consideration of one’s own subjective bias in the research process; on the basis that as social researchers, we are integral to the social world we study (Mauthner & Doucet, 2003).

3.3.4. Reflexivity

Since qualitative research acknowledges that the research and researcher are inevitably intertwined, it was important in this research that I maintained disciplined reflection throughout the process. Etherington (2004) states “to be reflexive is to be aware of our personal responses and to be able to make choices about how we use them” (p. 19). During this research, I was aware that my work within the field of ID and my views of working within disability services could lead to my understandings being prioritised and privileged, and the views of participants being insufficiently heard. I have, therefore, paid close attention to my assumptions, values, research choices and methods and interpretations of the data throughout the research process by building in dedicated periods and contexts for reflection, both with my research supervisor and peers. I also maintained a reflexive journal (See Appendix O, for example of Reflexive journal extracts).

Maintaining a reflexive journal is recommended in qualitative research in order to reflect on practice and keep track of the research process, so that the researcher’s bias can be captured (Lincoln & Guba, 1985). Reflexivity pertains to acknowledging “a researcher’s background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate and the framing and communications of conclusions” (Maltreud, 2001, p.483-484).

Given my own personal experience and working over 20 years within the field of ID, it is inevitable that I would bring certain assumptions and expectations to the research topic. I therefore, needed to be mindful to not allow my own preconceptions to shape my interpretation of the data. My reflexive journal enabled me to maintain some impartiality in the interviews with participants and during the data analysis phase. I sought to have the voices of participants to be at the forefront with my role being to sensitively and accurately describe their experiences.

My research journal showed how I had experiences of being anxious about the verbal skills of some of the participants with ID and their struggle to communicate their experiences. I realised upon listening back to interviews that I may have occasionally spoken for participants. As I reflected on the process and had discussions with my supervisor, I realised that all the data was valid even that from interviews I did not think were long enough or where participants had not much to say or struggled to articulate their experiences. My reflective journal was an essential part throughout my research journey, in ensuring rigour and helping me to maintain transparency throughout the research process.

3.4. Ethical Considerations

3.4.1. Ethical Approval

The ethical guidelines of the Metanoia Institute, the British Psychological Society and UK council for Psychotherapy (UKCP) were adhered to throughout this research process. In addition, ethical guidelines issued by the Irish National Disability Authority (NDA, 2009) were followed in designing the study and throughout the research process. Ethical approval was obtained from Middlesex University/Metanoia Institute (See Appendix D for confirmation of ethical approval) along with an approved ‘Research Undertaking Agreement’ from the Disability organisation (See letter of approval to conduct research within the organisation in Appendices B & C). The change in methodology was reviewed and granted approval, as a minor amendment, to my original application by the Metanoia Research Ethics Committee (See Appendix E).

3.5. The Setting

This study took place in a ‘not for profit’ disability service situated in the Republic of Ireland. The service nationally provides day and residential services to approximately 6,500 people presenting with ID. Service users are allocated a placement within the service based on an Assessment of Need, completed by a Multidisciplinary team usually a Psychologist, Social Worker and Psychiatrist and the appropriate provision of government funding is allocated to the service via the HSE.

The service in which I conducted my research is one of 6 regional services located within 8 counties throughout the Island of Ireland. There is a national and regional management structure however, given the scale of the organisation I will provide the regional structure for the service in which I conducted my research in only ‘Region A’ (See Figure 1 below). For the purpose of confidentiality I have chosen to not name the service.

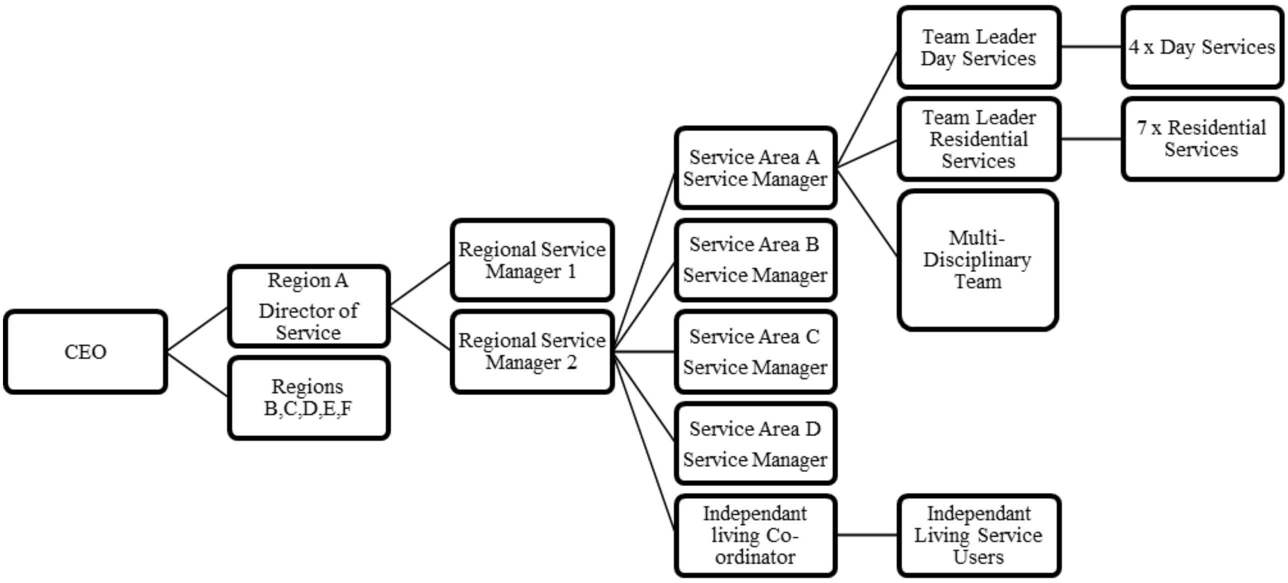

Figure 1 ***Organisational Structure of disability service***

The disability service I conducted my research in is spread across two counties in the Republic of Ireland. The service is managed by a Director of Services and two Regional Service Managers. Each regional area has a number of service communities providing both day and residential services to adults presenting with ID. The service presents with an ethos in line with government policy and the rights based approach towards providing people with ID the right to person centred services (HSE, 2018).

Service user reasons for coming to reside within the service were varied and all were assessed by a multi-disciplinary team (psychologist, psychiatrist and social worker) to require different levels of support from staff. Service users interviewed were all living in modern homes within local neighbourhoods and had different levels of staff support based on their assessed individual need.

The service community 'Service Area A' in which I conducted my research provides day and residential services to 50 adults presenting with ID and employment to approximately 105 managers and social care staff. The disability service also employs approximately 13 multi-disciplinary professionals including; psychiatrists, psychologists, social workers and speech and language therapists.

3.6. Recruiting a disability service

I wrote to a number of disability services within the Republic of Ireland providing an outline of my proposed research study seeking to conduct an ethnographic study, which would involve immersing myself within the culture of residential services. One service expressed interest and arranged for me to meet with the Regional Service Manager to discuss consent and access to participants. In the absence of an Ethics Committee within the service I was asked to complete a 'Research Undertaking Agreement' (See Appendix B) in order to satisfy the organisational policy on conducting research within the service. This was reviewed and discussed by the Board of Management and I received a letter of approval from the Director of Services to conduct my research within the service (See Appendix C). I was assigned a research liaison, manager within the service, who would support me in contacting residential services and who I could rely on for support should I have any difficulties in engaging in my research. The research liaison provided me with the email and postal addresses of residential houses within the service, and it was agreed that I would forward them my recruitment letter (See Appendices F & G), which contained details of the study. Participants identities were anonymised to maintain confidentiality and were not disclosed to my research liaison.

3.6.1. Recruiting Participants

Braun & Clarke (2019) recommend between 10 to 20 participants for conducting a medium thematic analysis project for a professional doctorate, therefore, I aimed to recruit between 5 and 10 service users and between 5 and 10 staff. I used purposive criteria based sampling where participants are judged to be typical of a population. Therefore, it was important to select only participants who had; 1) ID and were currently living in community based residential services within the disability service and 2) Staff who were current employees supporting adults with ID who resided in community residential services within the disability service.

3.6.2. Recruiting participants with an intellectual disability

Typically adults with ID have been omitted from the disability discourse (Coons & Watson, 2013; Kitchin, 2000) with very little qualitative studies conducted in the field. Research has often been ‘done on’ adults with an ID rather than ‘with’ them (Coons & Watson, 2013). Research within the field of disability has often been from a positivist quantitative approach, such empirical research does not allow for a portrayal of the lived experience of adults with ID (Bollard, 2003; Irvine, 2010; McDonald & Patka, 2012). Qualitative research, like this study, which aims to provide a space for the voices of adults with ID, is therefore essential.

Adults with ID are considered both capable and willing to engage in the process of a research study once it is meaningful to them (McDonald, Kidney & Patka, 2012). The barriers that have often hindered participation are most commonly issues of consent and determining capacity to participate (NDA, 2009).

After careful consideration, and in light of a change in research design where data to be analysed would be from interviews only, it was decided that in order to avoid any further difficulties relating to consent, as well as to maintain some homogeneity in terms of the participant group, the research was limited to individuals with mild to moderate ID (see section 1.1.2 above for definition).

According to the NDA 'Ethical Guidance for Research with People with Disabilities' consent to participate in research must be informed (NDA, 2009). My first step to honour this was to ensure the information provided to potential participants was accessible in order for participants to grasp the information. I consulted with a qualified Speech and Language Therapist who has over 30 years' experience working with adults with ID who formatted my initial 'easy-read' information sheet using pictures and simpler language (See Appendix G). Within the service I work for there is an advocacy group made up of adults with ID who use the service. I contacted this group to see if they would be willing to offer feedback on how accessible the information sheet was to them. They agreed, and as a result of their feedback I made a couple of changes to the original form to make the information as clear and concise as possible. These changes included; shortening some the sentences used to explain the research and also changing some of the pictures used, as some members of the group thought they were 'childish'.

I sent out an invitation, by post, to participate in my research to all service users with a mild to moderate ID who resided in each residential service within 'service area A' (see figure 1 above). I included two information sheets; an easy read accessible version and a standard version (See Appendices F & G).

As the disability service only provides residential services to adults from 18 years of age and over, age of participants did not factor as an ethical consideration. In sum, the following inclusion criteria were set for adults with ID;

1. To have a mild to moderate ID.
2. To be at least 18 years of age.
3. To be capable of giving informed consent as indicated by the researcher and direct care staff.
4. To be currently living in a residential community home accessing support from paid staff.

Exclusion criteria included;

1. Lack of an ID diagnosis, or having a diagnosed severe to profound ID; and
2. Acute psychotic or other mental health difficulties that would compromise their ability to give informed consent.

Six semi-structured interviews (Creswell, 2014) were conducted with six adults with ID. Three service users were female and three were male and their ages ranged from over 40 to over 60 years of age. At the time of the study four service users were also accessing day services within the same disability service. One service user was engaged in paid employment and one service user was ‘retired’ from day services. All but two service users lived with other adults with ID and two had moved from living with other adults with ID to now living alone ‘independently’. All had been accessing residential services between 7 and 38 years. While not a prerequisite of the study all but one service user had regular contact and support from family. Adults with ID who participated in this study are presented in the following table (Pseudonyms are used to protect participant’s identities);

Table 2 Service User Participant Demographics

Service User Participant Demographics

No.	Service User (Pseudonyms used)	Age	Gender	Total years living in residential services
1	“Ann”	38	Female	7 years
2	“Robert”	58	Male	38 years
3	“Stephen”	40	Male	17 years
4	“Angela”	65	Female	11 years
5	“Laura”	63	Female	14 years
6	“Michael”	49	Male	18 years

3.6.3. Recruiting Staff participants

The staff group were determined by the service user group whereby an invitation to participate in my research was sent out via email to all employed staff including; management, Multi-Disciplinary team and frontline staff employed within ‘Service area A’ (see figure 1 above). Staff were provided with the same two information sheets (See Appendices F & G) as issued to service users along with an invitation for me to meet with those interested in participating, so that I may explain in person what my research would entail.

For employed staff members to be interviewed as part of the study, the following inclusion criteria had to be fulfilled;

1. Currently employed within the disability service in which the study was being conducted.
2. Be providing support to service users who are current residents within the disability service.

The primary exclusion criteria for staff participants to be interviewed were not having supported adults with ID within residential services. Staff employed within the services ‘day services’ were not invited to participate. This was important given that the central focus of the research was to collect the perspectives and experiences of the lived experience of those who reside within the service.

Of the potential 105 staff invited to participate seven staff consented to be interviewed. Data from six semi-structured interviews (Creswell, 2014) are included in the findings, as one staff withdrew from the study prior to attending for interview. Five staff were female and one staff was male. Three staff were working frontline supporting service users in their homes, one manager, one supported living co-coordinator and one multi-disciplinary professional. Years working within the service ranged between 3 and 27 years. Staff who participated in this study are presented in the following table (Pseudonyms are used to protect participant's identities);

Table 3 Staff Participant Demographics

Staff Participant Demographics

No.	**Staff (Pseudonyms used)**	**Age**	**Gender**	**Role & Years working within the service**
1	"Maura"	42	Female	Social Care Worker – 27 years
2	"Breda"	54	Female	Manager – 25 years
3	"Brian"	32	Male	Team Leader – 10 years
4	"Liz"	51	Female	Social Worker – 3 years
5	"Lorraine"	44	Female	Social Care Worker - 18 years
6	"Claire"	40	Female	Supported Living Co-ordinator- 5 years

3.6.4. Consent process for people with intellectual disability

Bulmer (2001) said that 'Ethics is a matter of principled sensitivity to the rights of others' (p. 45). The NDA (2009) noted that there are 4 issues to look at to ensure that a research project involving adults with ID adequately addresses ethical concerns, i.e. informed consent, dealing with disclosure, acknowledging the right of refusal to take part in research and establishing appropriate support structures to deal with any effects which involvement in research could have on participants.

The primary ethical concern in research involving adults with ID relates to the extent to which such individuals are able to give informed consent to participate in research. Therefore, it was important that all potential participants were fully informed about the nature of the research and were made aware that they had a choice whether or not to participate and that they may withdraw at any stage. It is generally accepted that; capacity to consent is a continuum and that a person's capacity to make decisions may vary depending on the specific topic or area of life under consideration and that there are three requirements for informed/valid consent, that is the person must be able to;

1. Understand, retain and relay information and knowledge relevant to the decision (presented in understandable terms).
2. Understand the consequences of different actions/choices and weigh up the information to make a choice.
3. Make a voluntary decision i.e. understand that there is a choice, have the ability to indicate yes or no to communicate their choice (NDA, 2009).

This represents a particular challenge to adults with ID. They often have (i) a tendency to comply with the perceived demands of an authority figure (Parley, 2011) and (ii) a reduced capacity to understand and reason (NDA, 2009). The National Federation of National Bodies (NFNB, 2008) noted that the presumption should be of capacity even though communication difficulties and levels of intellectual disability raise concerns that informed consent may not be possible. In order to maximise each participant’s capacity to consent, as recommended by the NFNB guidelines, I developed an information sheet in consultation with a speech and language therapist which included; simple language, illustrations to present concrete information, information was presented in small, easy to understand chunks and during each meeting with potential participants I repeated the information several times, if it felt necessary. The information sheet and consent forms included appropriate information on the nature and aims of the research project and of the participant's involvement (See Appendices G & H).

I met with potential participant individually in their homes to explain the purpose of the study. Visuals (objects) and demonstrations were used in addition to the images on the information sheet and consent form to support this explanation e.g. recording equipment, pen and paper and sample interview question sheet. I asked questions to confirm that the person understood the key points. Participant's keyworkers were also provided with an information sheet in order to further support the individual make an informed decision. After initial contact was made a follow up meeting was scheduled for a week later to assess the participant's capacity to retain and relay the information provided (NDA, 2009). The opportunity was also given at this point for potential participants to ask questions. It was also reiterated to all that they had the right to withdraw from the research at any time during the data collection phase. A consent form (see Appendix H) was given to each potential participant at this stage and it was agreed that I would return to gain written consent within one week and to arrange a suitable time to conduct the interview. A period of two weeks was allowed, so as to give potential participants' time to further process the information and discuss with others what would be involved and also to provide time for the person to reconsider their participation. As the research was taking place within the disability service participants lived, it was clearly communicated to each participant that the research was independent of their service provision and participation would in no way affect or compromise the support they received. A lack of capacity to consent to participate or risk concerns identified by me, the participants, keyworker or disability service would have led to potential participants being excluded from the study. However, no participant was excluded over the course of this study.

It was also made clear to potential participants that participation may cause some distress, such as triggering upsetting memories. Each person was invited to identify a person of support that could be contacted by me or their keyworker should they need support following participation in the study. In addition, it was made clear to service users that it was my professional and ethical obligation to disclose any concern relating to the threat of harm to self or other and that this was the only foreseeable cause to break confidentiality. In addition, in line with the safeguarding policy of the disability service regarding the reporting of abuse, the 'Designated Person' for the service was identified in the information sheet as the reporting person for any disclosure of abuse. It was the role of the 'Designated person' within the service to investigate any disclosure of abuse.

While written consent was given by each participant I considered the issue of consent as an on-going process rather than a one off decision made by each participant. Given my position in the field of ID I was very aware during this process of my constructed 'power' in relationship with adults with ID. In order to avoid acquiescence and the desire to please, which has been highlighted to occur when researching people with ID (Finlay & Lyons, 2001; Smith, Polloway, Patton & Beyer, 2008), I did not rush to take potential participants first agreement to participate as consent. I afforded each participant with as much time as they needed to convey that I equally welcomed their right to refuse.

3.6.5. Consent process for Staff

Following an email to all staff employed within 'Service Area A' inviting staff to participate in the study, seven staff expressed an interest, and made themselves available to attend an initial information meeting. I met with each interested staff participant individually to explain the purpose of the study in either their place of work or in an office that was made available to me to use for the purpose of conducting interviews in the service. During the initial contact meeting I endeavoured to make the information and discussion about the research process as clear and comprehensible as possible in order to facilitate the participant's decision making. Staff participants were equally informed that they had the right to withdraw from the research at any time during the data collection phase. It was also made clear to potential staff participants that participation may cause some distress and advised of the supports available to them, specifically through their Employee Assistance Programme (EAP), which offered all staff with up to 4 free counselling sessions should they require support during or following participation in the study. In addition, it was made clear to all staff participants that it was my professional and ethical obligation to disclose any concern relating to the threat of harm to self or other and that this was the only foreseeable cause to break confidentiality. In addition, in line with the safeguarding policy of the disability service regarding the reporting of abuse, the 'Designated Person' for the service was identified in the information sheet as the reporting person for any disclosure of abuse (same as above for participants with ID). During the initial contact meeting staff were provided with the opportunity to ask questions. A consent form was given to each staff participant at this stage and it was agreed that they would take time to digest the information and bring a signed consent form with them on the day attending for interview. As the research was taking place within the disability service staff were employed in, it was clearly communicated to each participant that the research was independent of their employment and participation would in no way affect or compromise their job.

3.6.6. Confidentiality

As the interviews were concerned with details of service user and staff lived experiences the study was sensitive to issues relating to anonymity (Willig, 2001). In order to protect confidentiality for all the research participants the following measures were adhered to;

1. Pseudonyms were used in all interviews and notes to protect participant's confidentiality ensuring that the services, staff and adults with ID are not identified.

2. Participants were also assured throughout the research process that anonymity and data protection would be upheld, in accordance with The General Data Protection Regulation (‘GDPR’) and the Data Protection Acts, 1988-2018 (Government of Ireland, 2018).
3. Participant’s names and any other identifying information were omitted. Interview recordings were deleted from the digital recorder, once transcribed and transcripts were stored in an encrypted, hidden drive on the researcher’s password-protected laptop and any notes along with my reflexive journal were stored in a locked filing cabinet, in a locked office and will be destroyed two years after completion of the research project.

These commitments towards confidentiality were made explicit to each participant in the information sheet (see Appendices F & G) and during discussion with each participant during the consent process. It was also explained to participants that it was my hope to publish the study results and in doing so I would continue to protect their anonymity by changing names and ensuring the service was not named. Quotations have also been checked with participants either in person, via email or phone in accordance with participant’s preference to ensure that I have used their statements in context and that each quote accurately represents their views.

3.6.7. Risk of harm or distress

During the consent process participants both service users and staff were given the opportunity to explore the impact participating in the research study may have upon them. It was made explicit that taking part might make participants feel upset, or may trigger upsetting memories. Given my training and background, I saw myself as being able to sensitively and appropriately respond to any participant should they show signs of distress. The provision of support was built into the research design as mentioned above and service user keyworkers were also asked to contact me if they had any concern regarding the mood or behaviour of participants following participation, so that if a referral needed to made to the participant’s psychologist that could be acted on quickly.

During each interview (section 3.7 below documents the interview process in more detail) I was alert to the impact the interview had on each participant, should a participant become distressed during the interview process, I would have stopped the interview and provided the participant with debriefing and support.

I was contacted by one keyworker following an interview who stated that it had been noted that the participant was “energised” after the interview and seeking to want to make changes to his service. It was noted that this was a positive affect from participation and not an indication of distress. It was agreed that the keyworker would be best to listen to what the service user was seeking to do and provide appropriate support. I followed up two days later with both the service user and the keyworker over the phone and was informed that the service user intended to join a local advocacy group and write a letter to government about the lack of funding supports to his service. One service user also contacted me after the study to seek a copy of the findings. An easy read account of my study findings were provided to the participant on completion of the research study (see Appendix P). To the best of my knowledge none of the staff members indicated any sign of distress during the research process, nor made contact with me following their interviews.

3.7. Interview process

Using semi-structured interviews (Creswell, 2014) I interviewed twelve participants; six service users and six staff which allowed for a variety of perspectives emerge. I initiated building rapport by providing participants with information about the research topic (see Appendices F & G) prior to attending for interview, so that they would have some knowledge of what to expect and what we would talk about during the interview. During the interview I approached each participant with an open and curious attitude, stating specifically why I was interested in their point of view (McGrath, Palmgren & Liljedahl, 2019). Each interview began with simple questions, such as ‘when did you come to live/work in the service’, in order to make participants comfortable and settle into being interviewed. Each participant was provided with space and time to say what they wished to and they were not rushed to complete the interview. Each participant was interviewed once, interviews ranged from 30 minutes to 2 hours. The flow of each interview was guided by a semi-structured interview schedule (see Appendix J); however, I allowed for the interviews to take a natural flow only adhering to the schedule as a guide, if I needed to prompt the interview back on track. The duration of each interview was determined by the participant having said all that they wished to in response to us having covered all the key issues, and my feeling that I had received sufficient information (Braun & Clarke, 2006). Each interview was recorded using a portable digital audio recording device. Each participant was met individually in a location of their choosing, as long as privacy and confidentiality could be upheld. I met four service users in their home in a private room where the interviews were not disturbed and all other participants were met with in an office that was made available to me to use in the disability service for the purpose of conducting interviews.

The interview schedule was developed on the basis of the research objectives (see section 2.6, above). The interview was designed to yield information from both the service user and staff perspective. Both groups of participants were asked similar questions, starting with providing me with an account of how they came to live or work within the service. Participants were asked what they considered to be the aims of the service and what challenges they met in implementing these. I was curious about how this was translated across groups. Participants were then asked about their experience of person-centeredness and how service users were supported to live within the service.

Based on the literature, regarding how the quality of relationships experienced between service users and staff can determine more positive outcomes in terms of quality of life (Hastings, 2010), participants were asked how they experience the relationship with staff or service users. As this was an iterative process, and as I gained new insights and knowledge throughout the process, the questions at times were adapted and changed depending on who was being interviewed, in order to enhance applicability of the questions (Polkinghorne, 2005). After each interview, once the digital recorder was turned off, participants were offered the opportunity to debrief, discuss how they experienced the interview and to ask any questions. I also took time after each interview to write down my thoughts and reflections of the interview process in my reflexive journal (See Appendix O, for example of Reflexive journal extracts).

3.8. Data Analysis

The process of data analysis was approached following the 6-step framework for thematic analysis by Braun & Clarke (2006) (see Table 4 below). Braun & Clarke's framework provided a clear and usable framework and also offered flexibility which enabled me to organise the data produced from semi-structured interviews across both participant groups. Clarke & Braun (2013) warn against using the main interview questions as the themes and recommend that a good thematic analysis identifies patterns through an inductive process that are important or interesting and say something to address the research aim and objectives.

Table 4 Braun & Clarke's six-step framework for doing thematic analysis

'Braun & Clarke's six-step framework for doing thematic analysis

Step 1: Become familiar with the data	Step 4: Review themes
Step 2: Generate initial codes	Step 5: Define themes
Step 3: Search for themes	Step 6: Write up

3.8.1. Step 1: Become familiar with the data

I sought to familiarise myself with each interview listening to the recording several times. Each interview was transcribed by the researcher and anonymised. While I conducted interviews with service users first before interviewing staff the process and routine of data analysis was the same for both groups.

For each participant I read and re-read each transcript. I made initial notes and jotted down my early impressions on each page, underlying, highlighting or circling sentences or sections that were of interest (See Appendix K). I opted against using an electronic system to support my analysis (e.g.

NVivo) as I felt closer to the data as I developed my own routine and strategies (described below) to list the emerging themes by hand. I found this process of handling pages and pages of data equally chaotic, as it was fascinating, as I observed the developing themes (described below) and the shape of my research findings begin to emerge. I also found this process emotional, as I bore witness to the lives of adults with ID who expressed difficult experiences and the emerging frustrations of support staff. I noted my own reflections in my journal during this process (see Appendix O, for example of Reflexive journal extracts) and also utilised supervision to enable me to process my feelings, as I struggled at times to focus my role, as researcher, amidst the weight of therapeutic need I was exposed to.

3.8.2. Step 2: Generate initial codes

As I was seeking to address a specific research question I analysed the data with an inductive approach, whereby I coded each segment of data that was relevant to or captured something interesting about the experiences of adults with ID and staff. I did not code every line or piece of text, codes were developed as I worked through coding each transcript. Once these initial codes had been identified I grouped them together with other similar codes developing initial sub-thematic categories.

I discussed my initial ideas about the emerging categories with my research supervisor and began to identify the merging sub-themes and themes and tabulated these for further analysis (See Appendix K). Each group was analysed separately developing initial codes for the service user and staff groups separately.

3.8.3. Step 3: Search for themes

Braun and Clarke (2006) discuss that a theme is characterized by its significance and therefore, there are no “hard and fast rules about what makes a theme” (Maguire & Delahunt, 2017, p.3356). At this stage all the initial codes from each transcript were collated into one table (See Appendix L) and emerging sub-themes identified. Sub-themes and themes were continually reviewed until I judged them to be consistent across all participants within each group and at the participant level, supported by relevant quotes and named appropriately (see Appendix L). All the emerging themes were re-examined alongside re-reading each transcript. The identified sub-themes and themes which emerged up from the data for each group separately are outlined in Figures 1 and 2 below and are intended to provide a rich and detailed description of the data (Braun & Clarke, 2006).

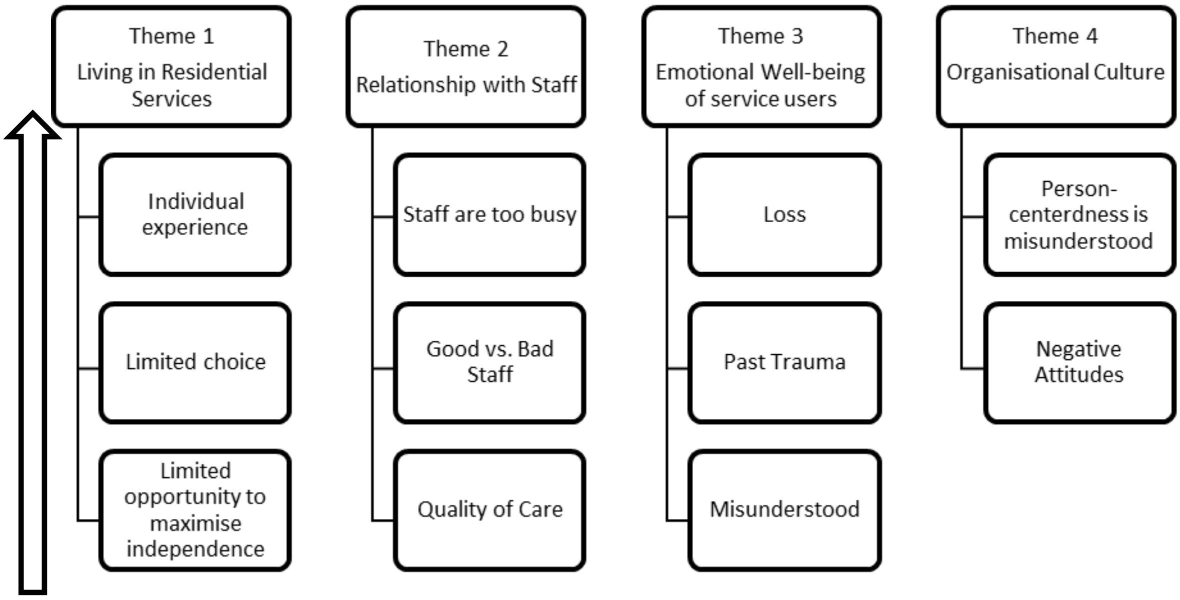

Figure 2 Visual overview of service user emerging themes and sub-themes

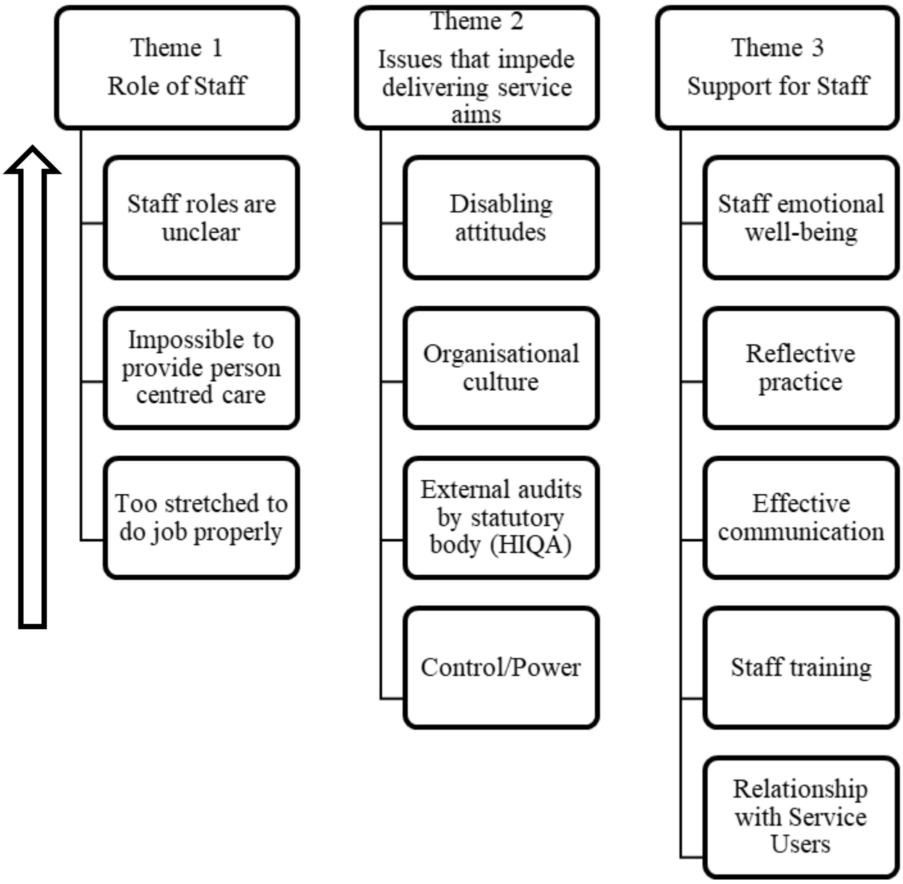

Figure 3 Visual overview of staff emerging themes and sub-themes

3.8.4. Step 4 & 5: Review and Define Themes

During this phase in discussion with my supervisor I went through each developed preliminary theme asking ‘does this make sense’. I then gathered all the data that was relevant to each theme and using ‘post it’ notes developed a moveable map that allowed me to create a thematic map of the emerging themes that were common across both groups (See Appendix M). This process was more about identifying the patterns in the data set and less about the quantity or proportion of themes that emerged. At this point a synthesis of the emerging themes was produced and three dominant themes were identified across both groups;

1) Conflict in the relationship between service users and staff.
2) Challenges to delivering person-centred care.
3) Shared needs

As each theme, and relevant sub-themes, were named and defined the narrative description of each theme was detailed documenting how each theme related to the other themes and to the overall research aim (See Chapter 4 Findings and Appendix N Defining and naming themes).

3.9. Trustworthiness

In researching an area of personal and professional interest I was mindful of providing a detailed and transparent account of the data analysis process and being open to how my own values and experiences may have influenced the research at the different stages, so that this study may be judged to be trustworthy. Trustworthiness in qualitative research refers to quality, authenticity and truthfulness of findings and relates to the degree of trust, or confidence, readers have in the results (Cypress, 2017).

In order to ensure trustworthiness, I utilised a number of measures to demonstrate that the data collection and analysis process have been conducted properly and meet the benchmark of quality by using the identified four criteria; credibility, transferability, dependability and confirmability, as set out by Lincoln & Guba (1985).

3.9.1. Credibility

This phenomenological study aimed to explore the lived experience of adults with ID and staff. As this study was phenomenological it was the researchers own interpretation of the data which stands. However, it was important that credibility of the research can be assessed. Credibility seeks to address the issue of ‘fit’ between participant’s accounts and the researcher’s representation of them (Koch, 2006). The following strategies were employed in this research to ensure accuracy of recording the phenomenon under investigation, through prolonged engagement with each participant, member checking, thick description and an audit trail.

In order to give credibility and coherence to the study, I conducted a thorough examination of the literature on abuse and ID, and critically compared my findings, in order to establish if there was resonance with the existing research, and whether the findings would have credibility for other practitioners and researchers within the field of ID. Thick description of the research is provided (See section 3.9 below) to ensure transparency with regards my position in the research. I have also provided a thick description of the setting and participants along with participants quotes in the findings to aid the reader to grasp what is being investigated, so that the reader may determine if the overall findings "ring true" (Shenton, 2004, p.64). Member checking was used to ensure credibility where I returned to participants and consulted with them to ensure descriptions given were authentic.

3.9.2. Transferability

Transferability means that a body of research's findings can 'fit' into other contexts outside of the current study situation. To enable others to evaluate the applicability of data to other contexts and settings, I have furnished enough descriptive data (See Appendices F to N) of the proposed study for comparisons to be made for future research (Shenton, 2004).

3.9.3. Dependability

Dependability within research ensures that a future researcher may be able to repeat the work (Shenton, 2004), with this in mind I have provided a detailed account of the practices and processes followed in this study through an audit trail, a full descriptive methodology, detailed examples of the analysis and examples of extracts of the journey to the research findings (Appendices K to O).

3.9.4. Confirmability

To achieve confirmability, I have provided a detailed audit trail and thematic maps to outline the process of data collection; analysis and interpretation (see Appendices K to N). I have maintained a reflexive presence in my writing documenting my thoughts throughout the research process (see Appendix O for reflexive journal extracts), providing a rationale for why codes merged together and providing an explanation of what themes mean. At all times throughout the research process, I have made clear my position within the research. I have questioned my background and position, continually checking to see how this has influenced the process, practically, emotionally and cognitively (Braun & Clarke, 2006). To the best of my ability, I took care to ensure that my analyses and interpretations were grounded in the data and honoured the experiences of the participants at all times.

Chapter 4. FINDINGS

4.1. Chapter outline

This chapter presents an overview of the three overarching themes and corresponding sub-themes identified from the twelve interviews. Each overarching theme and its sub-themes are discussed in turn and I conclude by giving a synopsis of the main study findings.

4.2. Overarching Themes

The overarching themes are represented in the majority of interviews while the corresponding sub-themes have greater variability and may not represent the perspectives and experiences of all of the participants. Appendix N provides a detailed elaboration of the overarching themes including sample quotes from participants. The overarching themes are;

1. Conflict in the relational dynamic between service users and staff
2. Challenges to delivering person-centred care
3. Shared needs

4.3. Overarching Theme 1: Conflict in the relational dynamic between service users and staff

In this theme participants discuss their experience of the relationship between staff and adults with ID and their experiences of the challenges negotiating between the personal and professional relationship. Several participants indicate that there is conflict with how service users and staff should be in relationship with one another. There is a blurring of boundaries between the personal and professional relationship with many service users experiencing staff ‘as more than just carers’ and with many staff experiencing adults with ID as a ‘vulnerable person’ they are paid to support. Participants reflect that there is a tendency to prioritise meeting services user’s basic needs with very little time to address an individual’s emotional needs. There was a sense from staff that it is best to ‘not get too close’ and not allow service users to become over dependent. However, for service users they reflected that it was important for staff to get to know them and they valued those staff who saw them for the people they really are. Also, within this relationship participants describe paternalistic attitudes which dehumanise adults with ID highlighting ‘otherness’ which positions adults with ID as different and ‘less than’.

4.3.1. Sub-theme (i): Imbalance of power

This study sought to understand the relationship between adults with ID and staff by asking service users and staff living and working in a disability service about their experiences. Participants reflect the imbalance of power in this relationship and the role each plays in this relational dynamic. Service users described how they were dependent upon staff support to assist them to live a life of their choosing, to help them with daily living tasks and to organise and plan social outings and activities -

> **Ann (service user)** says “Staff are good craic” (119)
>
> **Michael (service user)** says “Staff are important, to get things done, making sure I have everything” (176-184)
>
> **Angela (service user)** says “staff are very helpful and very supportive” (221-222)
>
> **Stephen (service user)** says “staff gave me more courage and more helpful” (66-67)
>
> **Laura (service user)** says “staff looking after me” (334)
>
> **Robert (service user)** says “like people who need to be brought places and taken care of, like who need to be put in a wheelchair, who need to be looked after; who needs to be organised, who need to be fed” (388-390).

I sensed that service users saw themselves as vulnerable adults dependent upon this care for their survival. This need placed service users with little control about who would support them and mirrors how adults with ID can have power and control exercised over them by others. Robert (service user) shares his annoyance of not having power and control over who supports him when he describes that he must at times accept ‘strangers’ to come and assist him in his home -

> “I should have more than a say in that because it’s my house at the end of the day. So it’s up to me to say who I should bring in and who I shouldn’t” (254-255).

Similarly, Maura (Staff) describes the challenge she faced when trying to support a service user to be involved in the interview process to choose his 1:1 personal assistant –

> “I remember we were looking at how can we get him actively involved in choosing the person…he would be told about the candidates and their pictures would be taken, you know he would be included….and I can remember at the first stage interview arguing with the residential manager because he didn’t want this particular person (staff)” (453-455).

In this case the preference and choice of a service user was being threatened by the preference of the manager and only that Maura (staff) was a robust advocate she was able to challenge her manager and advocate strongly on behalf of the service users right to choose.

I wondered about the impact of this reality, being positioned as vulnerable means that you must accept care from anyone who is willing to provide it. Claire (staff) reflects the unnaturalness of this relationship when she describes that staff and services users are ‘*forced*’ to be in relationship with each other -

> “But we’re forced to be in their life because we’re a paid service in their life, and they’re forced to have to accept us” (701-703).

Claire (staff) describes the tension she holds, as she both recognises the value of her relationship with service users, but also that’s its meaning is not the same for her as she is paid to be there and can leave at any time she chooses -

> "we're paid to be in people's lives, we're never going to meet their needs, we can't because we're not their family; we're not there for the duration – whenever you're or mine duration in life is – you know, the balance of control is out completely, because if I hand in my notice in the morning, all of the people I've spent two years getting to know lose me" (717-721).

Claire describes how aware she is of the central role she plays in the lives of many adults with ID and the impact of the loss of this relationship upon them. It is hard for her to hold this tension. How she coped with this reality was reflected in how she had come to develop practices that ensure adults with ID do not become 'too dependent' on staff –

> "We usually have two staff, so that people aren't overly-dependent on one person…so if somebody's off or they're out sick, and that's done in a very particular way, so that there isn't over-dependency. It gets really messy….it gets really messy…." (Claire, staff, 155-158).

The messiness which Claire describes refers to the discomfort and unease staff feel with regard to often being the main source of both emotional and practical support for service users. It seemed that staff were experiencing service users emotional 'dependency' upon them as 'bad' or 'not appropriate' and something that needed to be protected against by limiting service users contact with staff. Adults with ID's behaviour is often pathologised and interpreted as unusual. Claire's description '*It gets really messy'* is reflective of the common conceptualised view that adults with ID are not 'normal' and 'functional' human beings (Goodley, 2001). In this case staff were actively denying adults with ID's real human need to seek out an emotional attachment with staff, who are central to their lives.

Service users too reflected conflict within the relational dynamic with staff as they described staff as either 'good' or 'bad'. Valuing staff who do more than just provide basic care was reflected by a number of participants when they describe the difference between ‘good’ and ‘bad’ staff. ‘Good’ staff appeared to be those who were capable of engaging in a meaningful relationship with service users whereas ‘bad’ staff appeared to reflect staff whom service users experienced as not being ‘*cut out for the job*’ –

> **Robert (service user):** “ya see if it’s not the work for someone right, then they shouldn’t go into it” (235)

For Robert (service user) a ‘good’ staff was someone who spent time getting to really know service users –

> “There’s a little bit of an attitude yeah…not much…but I just think too that people (staff) should sit down with the lads (service users) and talk to them and say ‘well lads (service users) have ye any ideas for the weekend? Have ye anything planned? Is there anything ye’d like to do?” (189-191).

For Angela (service user) ‘good staff’ “*are very friendly people (staff) to live with…very helpful and very supportive*” (211-212). Robert (Service user) describes how in his view staff education bore little on how ‘good’ a staff person would be and that the job demanded instead commitment and an understanding of how the relationship between service users and staff impacts the quality of life of the person being supported;

> “Once the staff is sorted out, and they really need to be more focused on ourselves (service users) – well when they come into it they need to make sure of what they’re letting theirself in for. Because it’s not a job that you can say ‘oh I have the job now, I’m gonna take me time at it’. You have to know exactly what you’re letting yourself in for d’ya understand? It’s not a game…its lives…” (212-222).

How participants conceptualise the relationship between service users and staff as something beyond meeting basic care needs, but recognising the deeper relational dynamic of how the relationship with staff directly impacts their quality of life, demonstrates that adults with ID are very aware of the impact of ‘good’ and ‘bad’ relationships upon their lives and have very clear preferences about the kind of people they would like in their lives supporting them to achieve all that they can be. This raises for me how limited the opportunity for intimate relationships may be in the lives of adults with ID that the relationship with staff becomes one of the more significant relationships in their lives.

4.3.2. Sub-theme (ii): Loss

Despite the forced nature of this relationship for many adults with ID and staff, where relationships had existed over a period of time, it was clear that close emotional attachment relationships developed. However, the depth of this relationship was only fully realised when the relationship ended. Again, conflict was experienced by participants about how such loss should be expressed, managed and supported. What was most notable during participants interviews was the shared experience of little support, consideration or validation when these important relationships ended.

Stephen (service user) felt heartbroken when a staff he had come to develop a close relationship with over many years told him she was leaving. Stephen describes how he thought it must have been his fault that she was choosing to leave –

> ‘…Heartbroke….and meself and xxxx were very close, and I remember we were out and she told us she was leaving….and that was kind of a shock for me and like…. Em….sad and just I thought ‘fuck is it my fault’…’(240-243)

Stephen’s reaction to assume that it was his fault that the staff member was choosing to leave revealed how Stephen had internalised a stigmatised identity that impacted upon his self-esteem and how he came to see himself in relationship with others ‘*I just can’t have relationships*’ (252-253).

Stephen cared deeply about his relationship with this staff demonstrating his capacity to engage in a meaningful relationship. Stephen was not a passive recipient of care, but rather deeply valued how much this staff member had gone above and beyond in supporting him to live independently –

> “But it wasn’t like that, but it was ah…..it’s so sad because I know xxxx a long time, before…when I moved in….and then she took over as me key worker then….we did work together, and she exactly helped me with living on me own, she exactly done that with me….we done the health board – we done social welfare – we done everything, everything – got extra money from social welfare all that we done, and she was brilliant….” (247-252).

Service users were very clear about how the relationship with staff impacted upon their quality of life and they valued the qualities in staff who went above and beyond for them and took time to really get to know them as human beings. However, for staff how they should be in relationship with adults with ID challenged their views about maintaining boundaries between the personal and professional. Brian (staff) described his discomfort about how the relationship with staff is perceived by service users, which was in conflict with how staff experienced their role as paid professionals –

> “But a lot of the guys (adults with ID), if you asked them, they would see their staff as ‘friends’…they would say that like….which is interesting because they’re really not like the reality is would they be there otherwise if they weren’t being paid? You know, they’re in a profession. It’s an interesting dynamic” (561-564).

It is true that staff are paid to do a job, but how the relationship is experienced by service users, whom staff are there to support, can be seen very differently. This presents as a challenge for staff to address, particularly when relationships come to an end. Claire (staff) describes the real pain experienced by a service user she supports who is struggling to cope with and resolve the loss of a relationship with a staff member due to retirement -

> "It's an on-going loss and a grief that he's working through, that you or I would. He has no access to that person. You know we have no kind of "exit policy" around that. It depends on the staff – some of the staff will come back and have contact with people – some won't, and again that's where you're paid to be in somebody's life and it jars when they have to leave or they pass away, or the person is left with no control over that" (680-685).

Claire empathises with his grief and acknowledges that it is real in the same way it is for any of us, but she goes on to reflect how the service has no strategy of support around 'endings' to enable the person manage and process the loss. This further reflects how the significance of the relationship with staff is not fully realised within the disability service. The depth at which service users are impacted by this relationship does not inform practice and service users are often left bereft at the loss of these very significant relationships in their lives.

This need to protect staff from the 'messiness' of the relationship with service users was also reflected by Katy (staff) when she described the attitude of her manager when she was upset following the death of a service user she had supported for more than 10 years -

> "I suppose to be honest, and my manager would have said to me once, it's only a job, they're not your family….because actually when a resident died, I was quite upset. And it was said to me 'it's only a job like'….and I said 'it might be to you but it's not to me'….I was working probably 10 years with that person, and I just felt he was like a second part of my family" (131-137).

This quote captures the dichotomy between 'a job' and the very real human relationship that develops between two people. Katy was not given permission by her manager to be upset and to grieve the loss of this person she had grown to care about. I was struck how such a communication by her manager may also serve to dehumanise adults with ID that they should not be grieved over like any other person would be. This seemed to further reflect a cultural dimension within the service of what is considered ‘normal’ or not. Crying over the death of a friend would be conceptualised as an ordinary response that would garner sympathy and support, however in this example; crying over the death of an adult with ID, garnered a very cold and critical reaction. This reveals how adults with ID are subjected to very powerful underlying social processes that position them as something ‘other’ and dehumanises what it means to be in relationship with an adults with ID.

Similarly, Laura (service user) describes the level of emotion expressed when a staff member whom she had formed a relationship with over 14 years retired -

> “Yeah, because she didn’t want to leave and she came in roaring crying….and then we had a party for her….and she started roaring crying it was hard for her to leave….it was hard because we all got used to her. Getting someone in her place (will be hard)” (197-208)

Laura recognised the impact of the loss for the staff member and how hard it was for her to leave. Laura it seems was unable to express the loss in the same way “*I wouldn’t roar crying no*” (203) and I wondered if the staff’s tears were shed for them both. Laura’s reaction describes a denial of strong feelings, but also demonstrates how difficult it may be for her to verbalise her emotions. I was also taken aback by Laura’s experience of staff ‘roaring crying’; I wondered if a service user expressed such heightened emotion about loss would it be held and understood in the same way? The staff member’s tears can be understood in the context of retirement and what this transition may mean for the staff member but I wondered too if in Laura’s experience her muted reaction was a disavowal of needs whereby the emotional needs of adults with ID are not understood in the same way or are pathologised and so Laura may have learned to not be so emotional about it. It is also possible that Laura’s lack of emotion was because she had been here before and had seen staff come and go so frequently she was used to it. I also thought about the emotional space that was being taken up by the staff member’s emotional state and how in terms of emotional containment may not have provided Laura with a space to feel safe to express her own emotions about the staff member leaving. It was interesting that Laura reflected on how hard it would be to get someone else to replace the staff member highlighting the significance of the relationship with this particular staff person meant for Laura she was irreplaceable. I was struck too how hard it must be when a staff member leaves to know that the building of a relationship must start all over again. The loss of this relationship is more than just a staff member moving on, but a loss for service users of being known and understood by people who work intimately with them. Staff are more than just carers but a witness and companion in the unfolding lives of adults with ID. However, there didn't seem to be any acknowledgement of this for Laura or space for her to be with her feelings around this ending and its impact upon her. Suggesting staff's lack of relational awareness and ability to hold, contain and boundary their emotions enough in order to communicate to service users that they have the capacity to hold and contain their own emotions and those of the service users they are paid to support.

This shows that for adults with ID their relationship with staff is really important and staff play a significant role in meeting their emotional and practical needs. In some cases the relationship between service users and staff was experienced as more than just a job and close emotional attachments exist. However, there is uncertainty within the disability service around what is considered appropriate or not and there is some fear and discomfort about what it means should service users becoming too emotionally dependant and the impact of loss upon them.

4.3.3. Sub-theme (iii): 'Disabling attitudes'

The experience of 'disabling attitudes' by staff and service users were explored indicating that service users continue to meet attitudes that are driven by prejudice or stereotype. Staff described observing paternalistic attitudes that disabled the autonomy of service users. Maura (staff) described witnessing a staff member speak to an adult service user as though they were a young child;

> "eat all your dinner or you're not getting ice-cream" – these are adults – I speak to my grandchild like that you know" (175-176).

Similarly, Brian (Staff) described observing a staff member make a decision that would have resulted in an individual miss out on the end of a movie at the cinema in order to return home for the administration of medication;

> "it was the staff that said 'oh I think we'd better go we have to be back for 1pm to give tablets…it was defeating the value of the person's (service user) opinion to go watch a film…I think it more importantly devalued the person (service user), because like they're kinda saying "well shur they don't care whether they saw it or not" (229-239).

Such attitudes reflect the roles that adults with ID are often cast. In these examples above, adults with ID have been imposed with identities such as the 'eternal child' and 'incompetent'. These de-valued positions have consequences including; low expectations and the provision of fewer opportunities. Robert (service user) describes how others opinion of him as incompetent prevented him from accessing the opportunity to live independently when he was a younger man -

> "Well I don't like people (service users) being judged…sometimes people (service users) do be judged….which is not nice. I know people (staff) judged me…They thought I wouldn't be better than any of the rest of them….that I wouldn't have got where I am today" (177-181).

Staff opinion of him restricted his opportunities and demonstrates the process of stigmatisation and dehumanisation, whereby it was unexpected that Robert would be competent enough to live independently. Robert was not to blame for this, rather this reflects the consequence of the environmental and societal forces that maintain such injustices in the lives of adults with ID. Robert's (service user) resilience against such attitudes enabled him to finally live independently after 20 years of living within an institution.

Participants reflect that breaking the cycle of such disabling attitudes is a challenge, as they describe a culture within the service whereby such attitudes are passed down and hard to change;

> "I just think we still have an awful attitude…maybe it's an older generation, I hope….because I certainly don't have that attitude, so I'm hoping…but then again the attitude tends to be passed down anyway, so it's hard to break that cycle" (Brian – Staff, 408-411).

Katy (Staff) too reflected on how 'older' staff appeared to have a more controlling attitude toward service users -

> "but I do feel that with the older staff definitely institutionalised – 'my lads my house'...I worked with a person for ten years that said to me 'my lads my house'…Like some of the residents I work with now would say to other staff members 'ah the boss is on this evening'" (306-312).

Staff describe how such attitudes are enabled to flourish within the service as a result of very little over-sight and supervision with regard to their work. Maura (staff) describes the lack of supervision she receives and how she could be doing anything and no-one would know-

> "staff are not held accountable….you know and if you're not held accountable you know what I mean then…especially when you're working on your own in a house – you're there - I go in on a Friday evening at half past 3, and finish at half 9 Monday morning – there's no one….I could be doing whatever I want really!" (189-193).

It seems that such attitudes go unchallenged and there are not enough structures in place within the disability service that allow for such complex social processes to be reflected upon and questioned.

4.4. Overarching Theme 2 - "Challenges to delivering person-centred care"

Participant's experience and understanding of person-centred care was varied. Within the context of this disability service person centred care is a framework that guides how to improve the quality of life for adults with ID living in residential services through the promotion of healthful relationships and person centred cultures within the disability service (HSE, 2018). For many of the participants their understanding of a person-centred care framework was confused with person-centred planning, which is the process of problem-solving used to help adults with ID to plan for their future. However, as will be outlined in the sub-themes to follow participants experience demonstrated that the culture of the disability service did not enable service users to exercise power and control in how they choose to live their lives.

4.4.1. Sub theme (i): No shared understanding of person-centred care

The first sub-theme reflects participants varied understanding of the concept of person-centred care. Service users in particular did not have a sense that the framework of person centred care was aimed at delivering for them a service which enables them to live a life of their choosing and in which they were to be central. Only one service user interviewed stated that they heard of the term 'person-centred'. For the remaining service users they were most familiar with the acronym for person centred planning 'PCP'. And for the majority of service users interviewed 'PCP' referred to a meeting they had once a year as described by Michael, Laura and Angela-

> **Michael:** "Making sure I have everything….that's what it means" (184),
>
> **Laura:** "It's when…..it's the….when ya have meetings. We talk about going out places" (254-265)
>
> **Angela:** "Well a circle of support meeting is where (staff) asks you questions and you answer them as best as you can" (154-155).

Service users understanding of person-centred care related to their experience of the process of person-centred planning which for them was a meeting which was held once a year at which they were supported to identify goals and plans for their future. But even within the process of their person-centred planning meetings to plan for their futures Stephen (service user) and Ann (service user) did not experience choice and control, which is a fundamental principal of person-centred care–

> **Stephen:** "she'd (mother) have to talk privately or when I'm not around….now I come in then when you're (staff and mother) finished and then come back in….but that's what my PCP, something like that" (196-198)
>
> **Ann:** "the meeting is always with the parents…..to ask my folks….like my family, can I move out" (103-104).

Both Stephen and Ann describe how they experienced being absent from the decision making process and that their families in consultation with staff made decisions on their behalf. Both describe an indisputable power and seemed to accept that this was the 'normal' course of how decisions about their lives are made.

The struggle in understanding the concept of person-centred care was also reflected on by staff as echoed by Claire and Karen –

> **Claire:** "People think it's a plan and people are obsessed with thinking it's a plan and that plan has to be in date and that person has to have three goals…..we don't really look at 'this person is real'" (461-463).
>
> **Karen:** "It's very hard to define what it actually is when you sit down to try and define it, and what it means for each person themselves" (65-67).

Claire and Karen describe how the understanding of person-centred care is skewed by an organisational focus on planning and ensuring that there is a paper trail documenting three goals for service users. Both describe how seeing the real person and understanding what person centeredness means for them gets lost in this process. This was reflected by service users Stephen and Ann above, as they too describe being absent from the process. It seemed that within the service person-centeredness was reduced down to a tick boxing paper exercise and less about developing relationships and a person-centred culture that enables adults with ID to direct and be at the forefront of their own lives.

4.4.2. Sub-theme (ii): 'There is no choice'

The second sub-theme explores further service user's experience of not having power and control in how they choose to live their life. As illustrated by Brian (staff) his experience of service users having a choice was almost laughable and an illusion of person-centred care within the service –

> "I choose where I live" is normally one that I always….not like laugh at but I kind of go…..ya know this is not happening like….and I don't know how it will happen" (297-299)

This sentiment was shared by one of the managers Breda (staff) who reflects the tokenistic nature of delivering choice "*it can sometimes appear tokenism, and that that's an issue*" (126-127). Staff seem aware of the injustice that service users have little choice but powerless to change it. The constraints around choice-making was shared by Angela (service user) who seemed to have resigned acceptance that her choice to live independently would likely never happen –

> "Well I think that I would like to just live in an independent house if you like, with just one staff….but I don't suppose that's going to be possible no" (195-196).

For Michael (service user) and Laura (service user), while they were happy with the house they lived in and the staff who supported them, they were concerned about the incompatibility of other residents and the lack of choice around who they have to live with. For Michael the behaviours of other residents upset him "*I don't like people [service users] shouting*" (8). For Laura she struggled to engage in conversation with other service users "*it's hard to know what he is saying*" (472) leaving her to only converse with staff who invariably had little time to engage with her due to "*sometimes they could be very busy with the two of the lads*" (441-442). Both had raised this as an issue for them through their complaints process but knew there was little option for change anytime soon.

Staff and service users raised concern that the services were purchasing houses that were in the country and too far from community amenities, which has further limited service user's choice, increasing dependency on staff to support them access and integrate within their local community, contrary to the person-centred framework which endorses inclusion and social participation –

> **Ann (service user):** "The only problem with….the only thing wrong is it was in the country…it's far away from my mother's house… we drive up and down the country" (35-40).
>
> **Brian (staff):** "geographically looking at where you purchase houses and things as an organisation…ya know you want community living, but I've seen some houses and they're off the beaten track, and I can't understand the logic behind it" (422-425)

Again this highlights how service users are not central in the decision making processes and in this case, houses are purchased to satisfy a service need (e.g. cost) rather than the person-centred needs of service users.

The lack of inclusion of service users in decisions regarding their lives was evident during a number of interviews. Staff expressed their concern and frustration with how management made decisions quickly about service user's lives without any consultation with service users or with staff who know them and their preferences well. This appeared to be common practice and an on-going issue for staff, as highlighted by Katy (Staff)-

> "I only had an issue last week…and I had the manager coming only this evening to speak with a resident saying 'how are you feeling about moving out?'….and I'm sitting there looking at the manager saying 'are you for real?'". (628-631)

This reflects the inconsistency between what the disability service says it does through person centred policies and procedures and what really occurs through informal practices as described by Katy above. The reality for many participants is that delivering person-centeredness is an impossible task. This lack of autonomy with regard to who supports service users, or where and with whom they live, leaves service users as unequal partners in the delivery of care aimed at meeting their needs. Maura (staff) expressed her concern that change was only likely to occur if a serious risk was identified –

> "But why wait until something goes wrong? You know, why not. And we're aware of situations in services at the current moment that….you know…..I suppose some staff feel like…what's the last resort?" (210-212).

And in the absence of serious risk the process of change in responding to service user's choices was experienced by many participants to occur very slowly. In describing how long he had to wait for his choice to live independently to be met by the services Stephen (Service user) remarks "*the system in there is very very slow*" (313). Karen (staff) shares this view that the process of change is slow "*You can see what needs to happen to support people in a way that you would like them to be supported, but it's so slow for change to be effective for them*" (30-31). This frustration appeared to have hampered expectations where service users and staff did not hope for positive change to occur quickly within the service; "*I think in ten years' time it'll be a bit better I hope*" (Karen – Staff – 47-48). Claire (staff) describes how morale has been affected by such slow progress and a lowering of expectations of what could be achieved –

> "…we take really good care of people, and we do our best day-to-day, and we do a really good job of doing that…..but more and more we can't do anything outside of that" (830-832).

Claire describes how attitudes are being shaped in the disability service, as a result of the challenges to delivering person-centred care and so many staff are now resigned to not being able to improve the quality of life of adults with ID outside of meeting the basic care needs of those they support. This reflects a significant social process about how the 'lowering expectations' of what can be achieved in the lives of adults with ID can be legitimised by the discourse of 'we take really good care of people'. This highlights the dominant cultural narrative of care within the service whereby service user outcomes are measured by how well staff perceive they are cared for versus service user's subjective experience of a good quality of life.

4.4.3. Sub-theme (iii): Funding crisis

All participants indicated that there were many constraints to delivering person-centred care of which they had no control. 'No money' and 'No time' were cited as the dominant reasons why staff were unable to fulfil their role in delivering person centred care.

Katy (staff) describes how the need to complete paperwork gets in the way of her spending time with service users –

> "I would rather spend the time with the individuals doing individualised stuff with them, than doing all the paperwork. That would definitely be my outlook on it" (Katy – Staff, 107-109).

There was a palpable strain evident in participant's accounts of wanting to be able to do more but feeling personal wants and needs were being overpowered by hierarchical organisational decisions.

The concern about lack of financial resources resonated with every participant interviewed. Katy (staff) expressed her frustration that there never seemed to be enough money within the budget to maintain the residential home -

> “Every time I look for something, a lick of paint on the walls, to clean the carpet on the stairs ‘don’t talk to me, no money no money’…I said to her ‘if I hear the words no bloody money once more’ (laughs), you know, where is it going?”(420-422).

The manager Breda expressed her fear that within the hierarchical system senior management had more of a focus on budgets rather than person-centeredness;

> “I’m fearful that the organisation is going towards focusing on budget as opposed to people, and when you go to senior management meetings that I find a challenge…that while we’re pontificating person-centeredness, on the other hand we’re saying “budget budget budget”. (291-295).

Service users too shared concerns regarding the funding crisis. Stephen spoke about how a lack of money was limiting his access to additional home support hours; “*But see the money is not there”* (Stephen – Service user - 161). Michael (service user) and Robert (Service user) also had awareness that the funding issue reflected a wider social and political concern that governments were not investing in disability services;

> **Michael:** “To give more for people with services I think….the government are not investing….I think the government should give more” (152-153)
>
> **Robert:** “they [the government] don’t have enough…maybe the funding is not there, but they should be giving a bit more, you know, extra money towards people who need the funding” (87-89).

There was a sense from participants that the service was stuck. Brian (staff) describes that the only way through this crisis was if more individualised funding could be guaranteed-

> “it all comes down to funding from what I can see…that they’re under the ‘bulk funding’ model, whereas I have visited all other day services…there was one service had 7 people using services and 7 staff…It just gives you some opportunity….that you can meet someone’s needs like” (151-157).

Katy (staff) describes the impact funding issues were having on the emotional well-being of service users -

> “they’re affected in every way by funding…let it be staffing…shortage of psychologists….we need more training to deal with certain things…they’re missing out on that, it might be small things to some people, but it’s big big things to them like” (Katy – Staff – 469-472).

I wondered if this need to blame external forces for a lack of resources and funding further legitimised the fate of adults with ID having to live in an unjust world. It would be more difficult to consider how the cultural attitudes, beliefs and values within the service were preventing adults with ID achieve a full and satisfying life. It seemed that all participants while accepting its injustice took comfort in being able to blame the ‘funding crisis’.

4.5. Overarching Theme 3 - “Shared Needs”

All participants reflected the need for greater support and training identifying their parallel needs. Participants indicated that in order to meet the needs of service users, staff also needed to feel supported in their work highlighting the dyadic nature of professional support.

4.5.1. Sub-theme (i) – Not enough support

Staff identified their needs for more support from management so that they may be better able to provide emotional support to service users; this is illustrated by Maura (staff)-

> “But if the emotional needs of staff aren’t met how can we meet the emotional needs of service users” (623-625)

Maura acknowledges that if staff do not feel supported in their work then this will have an effect on their capacity to provide emotional support to service users. Katy (staff) described how she does not feel valued and appreciated and there are no incentives within the service to motivate staff -

> “I’m just thinking my son was only on his apprenticeship six weeks and he was brought on a night out and €100 voucher at Christmas…so when I think about it…there’s no acknowledgement not at all! Years ago we used to have a staff night out but I don’t know, the money is not there now” (590-593).

This feeling of not being appreciated was echoed by Brian (staff) who spoke of the benefits of receiving positive feedback from management -

> “I always find I like to be told when I do something well, and I think that’s probably still lacking, and it’s something I’m trying to promote….and there is something nice about knowing you’ve done a job well” (521-525).

This suggested a lack of consistency by management to provide staff with on-going feedback on their performance leaving staff feeling un-motivated in their jobs. Staff seemed to be open to receiving feedback but that the processes in place were no longer being used for this purpose. Maura (staff) spoke how staff teams were provided with one day per quarter to come together and reflect and set goals with the aim of receiving feedback and improving performance. However, Maura's experience suggested that this day was no longer being used as designed and instead was being used for mandatory health and safety training or time to complete paperwork-

> "I believe team-based performance management was one of the best things that ever came into the Services – I don't think it's being utilised to its full potential, and I think it's now being used as staff to catch up on paperwork and that kind of stuff" (70-73).

This shift in purpose suggests that there is a growing culture in the disability organisation that communicates taking space and time for reflection and feedback is no longer important. Instead, as described by Katy (staff), the shift in focus is on health and safety, managing risk and completing paper-work.

> "there should be a meeting in the house maybe once a month or once every two months, so that everybody is kind of on the one page….that you're not second guessing or having to pick up the phone…then you'll have staff who will always ring you before you go in on duty if there's something big going on…or you'd ring them to refer do you know what I mean? Some staff would go out the door and say 'I'm finished my shift good luck' (246-251)

Staff describe that there is no space given to share personal feelings, to process challenging or upsetting events and also to receive feedback on their work in a constructive and supportive way. Maura (staff) described the importance of feeling a part of a team and that efforts to develop good team relationships was waning within the service-

> "I do believe one of the big things as an organisation we should be supporting staff and we're not…and I think people say "awh if I hear that word 'staff motivation' or 'I'm stressed or stretched' this again"…but we're not listening…" (94-96)

Breda (Manager) describes how difficult it is for her to provide her staff with the support she knows they need –

> “I’d try to be better at having conversations with staff, but it’s literally….like you’re so stretched that it’s almost….it’s a tick box to get to something else…so it’s a tick box for the HR Department…it’s a tick box for HIQA…and it’s not about the individual….and then on the one hand we’re saying that the service should be about person-centred…but it should be person-centred for both staff and the people supported….and certainly it’s not person-centred for staff, absolutely not…we don’t engage with people in any shape or form about positivity, and saying “do you know what, actually that’s really good”…. (433-441)

Staff refer to having access to an ‘Employee Assistance Program’ but that this service was thought to be offered too late and often in response to a crisis. Staff reflected the need for regular opportunities to meet with a professional to work through the emotional impact of their work on a general day to day basis and not in response to a crisis incident, as was often described as the case by Brian (staff);

> “Employee Assistance Scheme and that’s always thrown out when someone’s experienced a difficulty, but that’s nearly too late then because they’ve reached their threshold by then….I’ve discussed it with many people about professional supervision and the importance of it” (486-490)

Service users interviewed on the other hand appeared less able to make the same demands as staff for support. Efforts during interviews to explore their felt sense of the impact of living in residential services highlighted a need to enhance service user’s emotional vocabulary and insight. Of the six service users interviewed Stephen (service user) was the only one to refer to how he often feels lonely living in residential services; “*It’s lonely…it gets lonely*” (80). Claire (staff) describes how in her experience loneliness was one of the biggest issues that staff were unable to resolve for service users -

> “we can support them with the nuts and bolts of cooking and cleaning and house maintenance and that kind of em…the kind of nuts and bolts of keeping a home and how you pay your bills and all of that – but loneliness is probably…by far the biggest need that we can’t really” (55-58).

When seeking to explore service user’s experiences of seeking support participants spoke more frequently about how stressed and over worked staff were. Angela (service user) describes how she did not wish to burden staff with her needs for fear of causing staff any more stress –

> “Shur I don’t bother the staff really” (129)…..

> “…..I thinks that the staff have a big enough challenge with everything” (244).

The absence of service users expressed needs was very loud during the interviews and appeared to reflect the absence of discussion about the well-being of service users generally within the service. Service user’s needs and the impact of living in residential services on emotional well-being had only very recently (within the last 12 months) been added to the organisational safeguarding policy whereby ‘emotional abuse’ now stood alone highlighting service users right to be emotionally secure. While this change is in relation to challenging behaviour and the impact of living with someone who was aggressive, it did indicate a start toward developing the discourse around service users felt sense of living in residential services.

Claire (staff) reflected that how much information she has access to may not always be readily shared which can make it difficult for her to fully understand the needs of the adults with ID she is supporting-

> "you know I was kind of exploring whether he had trauma-related stuff going on in his life many years later, which I still think he has, but I was excluded from being able to view parts of his file because a professional decided that I couldn't do that" (267-270).

For Claire this represented the power struggle within the hierarchy of the disability service with regard to who makes decisions about what should be known about a service user's history and the impact this history may have on their day to day life.

In the absence of a verbal repertoire to describe one's own feelings service users often rely on the awareness and support of staff to be advocates on their behalf and recognise that they may be presenting with maladaptive ways of coping. While some staff had awareness of this need "*It isn't about their behaviour, it's about their wholeness and their well-being*" (Breda- Staff – 401-402) there was a shared concern according to Karen (staff) that staff do not have the time to prioritise the well-being of service users-

> "staff don't have the time to think about the emotional well-being of service users I think some people are…I'm not sure that the staff on the ground have the time to be thinking about the emotional needs…I think they're trying their best to do the physical care and the recording and the cleaning and the…..that the emotional needs would come way down on the priority list…unless the person is demanding something because of…but I think unless it's in their face like they're not thinking about it" (238-243).

It was a theme across interviews that service users' emotions continue to be thought of in the "*context of psychiatry not in the context of the normal ups and downs of life*" (Karen – Staff – 246-248). This need to rely on psychiatry to alleviate the emotional distress of service users and how this can leave staff feel frustrated was reflected on by Katy (Staff) when she described how a service user's mental health was being negatively impacted on by not having a consistent staff roster-

> "because one of our residents was all the time 'who's in today?' 'who's in tomorrow?'…and that person, you know, with OCD and the anxiety was building and building…and then I had the [nurse] telling me 'bring that person to [Psychiatrist]'…and I'm saying 'no'…and she's looking at me going 'who do you think you are?'…and I said 'under no circumstances am I having somebody medicated because of something that is not his own fault'" (448-454)

Pathologising adults with ID in this way reflects more of the medical model of disability, whereby a person's difficulties are seen as coming from within and not as a consequence of the person's interaction with their social environment, which reflects the more modern social model view. Such restricted thinking around the emotional well-being of service users was also reflected in how the opportunities to develop relationships beyond those established with family and paid support staff did not appear to exist for many interviewed. Stephen (service user) describes how he is "*waiting for a pal*" (99) through the volunteer program. It did not appear that outside of his paid support and family he had opportunities or much support to develop other meaningful relationships.

The very idea of service users having romantic relationships also appeared to be a grey area with staff feeling as though issues of capacity and uncertainty with the laws concerning sexuality made this difficult to pursue;

> "I can understand to an extent from a staff point of view, and even a family point of view too – we always use the 'c' word, the 'capacity'…if they were to have relationships with somebody…can they only have a relationship with someone with another disability? Or if they have a relationship with someone who didn't have a disability, what does that raise for people?" (Brian – Staff – 610-614).

The loss of such opportunity to develop intimate relationships was also felt by Robert (Service User) when he reflects that he did not have the opportunity to marry or have a family as the opportunity simply did not exist -

> "I never had that opportunity to bring up children on my own or to be married or anything like that….it just never happened for me and that was it". (264-267)

While the service involved has psychologists employed to provide psychological intervention and psychotherapy to service users it was the shared view that such psychological support was only in the event of a crisis. Robert (Service user) succinctly puts it when he reflects that service users are human too and have tantrums but other than doctors who do they have to talk to about their problems-

> "ya know a lot people gets emotional, there's always going to be an emotional thing in a person's life….everyone gets emotional….people in the town gets emotional….kids are bawling they get emotional….because they go into a tantrum because they can't get what they want….You're going to have service users who get into a shindig (354-362)

> " … Well there's people out there who need these doctors….but is there anyone there if anyone has a problem" (407-408)

Service users appeared to have greater access to their social workers when they were 'unhappy', as there was an established practice within the organisation that service users could use an "I'm not happy (INH)" card to report any grievance they experienced with regard to any aspect of their lives. Michael (service user) described how he has relied on the INH process to bring forward his complaints that there were not enough staff on duty to meet his needs-

> "Well there's always the not happy card…I think it's a good idea to have a not happy card…I used it when I didn't have enough staff" (221-226)

Access to timely support to cope with the experience of living in residential services for service users and staff was limited. Many other issues were prioritised within the disability service and support provided was often a response to risk management rather than seen as a necessary mechanism to ensure staff teams were motivated and performing well in order to enhance the quality of life of service users.

4.5.2. Sub-theme (ii) – Need for more time

The second sub-theme reflects the shared need for time. There was a sense from all interviewed that that there was little time to do anything. Laura (service user) describes how staff do not have time to support her to engage in community activities-

> “No-one brings me...staff have no time to bring me to the cinema” (230-232)

This was shared by Maura (staff) who also experienced not having time to engage in a meaningful way with service users -

> “I’m coming on at 4.30pm – by the time I pick up four individuals,; drive out to the house where we are; put on dinners; support somebody to use the bathroom; read the notes as I’ve been gone for a week – it’s 6 p.m. before dinner’s over; then you’re into the care plans, toilet plans, whatever….You know what I mean. And even if you’re just reading emails - that’s your day gone! So where in the name of god do you have time….and circle of support meetings; person centred planning all has to be done in this time” (362-370).

There was acknowledgment by Breda (manager) that the giving of ‘time’ would go a long way to supporting service users and staff-

> “the one thing you need to give both the people supported in the service and the staff is time….and that’s the biggest challenge in trying to manage your time accordingly, to be able to give people that time….because that can make all the difference to people at the end of the day” (364-367).

But the how of this remained a barrier given the cost implication for something else-

> "Because currently there is just literally no supervision. I mean we might pretend that we're….like you're not even….and I swore that in 2019 I'd try to be better at having conversations with staff, but it's literally….like you're so stretched that it's almost….it's a tick box to get to something else" (Breda – 431-434).

The burden of time was further reflected in how staff described being 'over-worked', 'stretched' and feeling stressed as they cope with many 'competing demands'. The risk for burnout seemed high as staff struggle to find a balance between providing support to service users and meeting the demands of the organisation. It seemed that the balance towards satisfying the demands of the organisation took priority over meeting the needs of service users; "I would love to go into work and sit with the girls and watch a movie…because I think that's important….but work has to be done" (Maura – Staff – 413-414).

4.5.3. Sub- theme (iii) – Need for training and supervision

Robert (service user) identifies that in his view staff would benefit from regular 'training' to discuss and review the realities of the job so that there was a shared understanding of how best to support service users-

> "I think there should be a training day for a staff….like every two weeks…ya know and then people[staff] will know…if I had my way I'd have a staff training day every two weeks, and that means then that whatever happens then in the houses, it's up to them [staff] to know exactly what to do " (242-245)

This was also reflected by Katy (Staff) who too felt it is important that staff have an opportunity to regularly come together-

> "there should be a meeting in the house maybe once a month or once every two months, so that everybody is kind of on the one page"(246-247)

The impact of the relationship between staff and service users reflected there was a need for staff to be supported through supervision or reflective practice as the demands of the job necessitated it. According to Claire (Staff) supervision was not valued within the disability service-

> “seen as nice and fluffy. But it’s actually essential I think – you know it’s something that keeps the staff well, which means we look after the people we support better – it nips things in the bud before they get out of hand or before people get to the point where they feel they’re not being valued, or that they can’t handle situations” (201-206)

The need for more training and supervision appeared to reflect a cultural dynamic within the organisation. Maura (staff) describes how the focus of attention within the disability service was often on what was wrong with the service and not what was good –

> “we’re always looking at what’s going wrong, and what needs to be done next – and we’re never looking at what we’ve actually achieved. And I think by sitting and reflecting in a nice way, and using that day, it gives people a sense of purpose; it gives them a sense of achievement; and it gives them a sense of motivation to go “oh ok let’s go ahead” (83-87).

The need for training opportunities for service users was also highlighted. According to those interviewed; service users received little training opportunities to enhance their skills toward meeting their needs. There were no group training initiatives to develop skills or develop emotional awareness despite as Karen (staff) highlighted there was a need for bereavement groups for example-

> “there’s a need in the service, but whether there’s scope I’m not so sure…but there’s a definite need to focus on it yeah…and as well on specific kind of support for issues like a bereavement group…but one a year isn’t enough, and for our people it’s often they might be told to go back a few times and even like groups on how to have friends…those kind of issues that people struggle with” (254-259).

Apart from ‘code of practice’ training at the point of induction staff reflected that they had few opportunities for professional development outside of attending mandatory health and safety training. Katy (Staff) reflects on how further training would enhance her ability to provide support and alleviate her felt sense of stress when she feels unskilled-

> “I do feel that staff need more training….if they’re expected to take on more, we need the training to take it on… like one resident I worked with is bipolar, and the anxiousness it just builds and builds and builds.. they don’t understand, it’s like ‘why have I to wait?’ ‘Why can’t you answer me?’….so maybe even if we were trained a little bit more in it?” (224-240)

The focus of training and support was mostly around keeping people safe and less about enhancing staff and services user’s personal and professional growth. This focus on risk management reflected that within the service adults with ID have been imposed with the identity of being ‘vulnerable’ who need protecting and it is this position that drives the thinking and behaviour around their care.

4.6. Synopsis of Findings

In sum, the aim of the research was to gain insight into the lived experience of adults with ID and staff of the social processes that impact upon person-centeredness in disability services. The research succeeded in establishing an understanding of the multi-dimensional and complex factors that can impact upon the quality of care experienced. The service delivery was hallmarked by the significance of relationships between service users and staff and the role this relationship plays in the understanding and meeting of service user’s needs. A deeper interpretation of the findings within the context of the literature will be outlined next in the discussion chapter.

Chapter 5. DISCUSSION

5.1. Introduction

The findings of this study reveal that there are many complexities to living in residential services that impact negatively upon the quality of life of adults with ID and may lead to poor and abusive practices developing. In this chapter, I aim to present a relational understanding of the social processes that exist, such as the dehumanisation of adults with ID within residential services. This research proposes that adults with ID who live in residential services are limited and constrained in their roles, behaviours, emotions and their voice by societal and relational processes (Greenhill, 2011). This chapter focuses on the key findings which emerged from the data gathered from the twelve interviews (See Chapter 4) and considers them in the context of the current models of disability, philosophies of care and previous literature. The chapter begins with a consideration of the main themes across both participant groups in this study. I then discuss the findings in relation to the following research objectives which guided this study;

1. Explore the nature of the relationship between adults with ID and staff.
2. Identify factors that impact upon person-centeredness in residential services.
3. Explore the nature of organisational culture in disability services and its impact upon the quality of life of adults with ID who live in residential services.

5.2. Themes across participants

The study aimed to explore the experiences of adults with ID who live in residential services, and their support staff, of the social processes that impact upon person-centeredness in disability services, and discover what their subjective experiences can tell us about the relational and cultural dynamics that exist in disability services, and their impact upon the quality of life of adults with ID who live in residential services.

Six adults with ID and six staff employed within the disability service were interviewed and the data analysed using thematic analysis. Three overarching themes emerged; 1) Complexity of relationships between service users and staff, 2) Challenges to delivering person-centred care and 3) Shared needs.

5.3. Theme 1: Conflict within the relational dynamic between service users and staff

This study has shown (Chapter 4) that for adults with ID their relationships with staff are really important to them and for many meaningful emotional attachments have been made. Adults with ID demonstrated a dependence on staff that went beyond meeting their basic needs (e.g. cooking meals, personal and intimate care tasks), whereby staff were also relied upon to meet their social and emotional needs too. This reflects the maturational process of many adults with ID and how they have grown to be dependent on others to meet their needs (Pitonyak, 2014). For many of the adults with ID interviewed they experienced staff as more than just ‘carers’, but saw them as friends and akin to family members. For some staff this was mutually reciprocated where they too had grown deep personal attachments to adults with ID that they had cared for, for many years, who too were seen as family to them. This study highlights the interdependent and dyadic nature of the relationship between adults with ID and staff in residential services.

This need to be ‘more than just carers’ was felt deeply by the staff interviewed and created a tension with regard to what is understood about boundaries between the professional and personal relationship. Staff felt a pull to meet the social and emotional needs of service users and provide support in many different situations such as; emotional regulation in the event of a service user presenting with anxiety or aggression, supporting service users who are bereaved, facilitating social training, developing friendships and so on. However, staff felt that meeting all of the needs of adults with ID was an impossible task for them in the context of the other many demands placed upon them.

Pressures in meeting organisational policy and practice issues left many staff feeling that the expectations of them in their role were too great. Staff reflected that such is the demand for ‘paper-work’, addressing ‘health and safety’ issues and meeting the demands placed upon them by managers to keep in line with HIQA standards meant that these tasks were often prioritised over meeting the human relational needs of adults with ID. This contradiction in service aims sat heavily upon staff who seemed to struggle with managing their time and a feeling of guilt around not fulfilling their role in providing support to adults with ID. This was felt by adults with ID too, who also felt the pressure staff were under and the limited time they had to spend time with them. I was particularly struck when Angela (service user) stated how she would not wish to further burden staff by asking them to take her to the cinema;

> “Shur I don’t bother the staff really” (129)…..
>
> “…..I thinks that the staff have a big enough challenge with everything” (244).

The reluctance to ask for staff to spend time with her engaging in a fun social activity reflected a shared theme around adaption and a disavowal of needs. Many of the adults with ID appeared to have adapted to living a restricted life and did not wish to use their voice and ask for more, for fear of being seen as ‘demanding’. Feeling burdensome was also identified in previous research by Dorozenko, Roberts & Bishop. (2015b) and suggests that adults with ID had internalised a stigmatised view of self. Highlighting how many adults with ID would have experienced the medical model of ID and experienced many negative impacts as a result. This confirms the effect of how being labelled with an ID, as described by Spassiani and Friedman (2014), becomes even more oppressive by the power dynamics that exist within relationships, particularly as shown by Angela’s dilemma above, when adults with ID struggle between their own desires and those of others.

I also felt from adults with ID a need to be grateful for the support they did receive and a reluctance to ‘rock the boat’. This tension between ‘doing what I would like’, but not at the cost of causing staff any more pressure, was felt amongst many of the adults with ID. A similar tension was felt amongst staff, whereby they also did not feel they had permission to do the job they wanted for fear they would ‘rock the boat’ with management, by needing to ask for more resources. This tension and conflict between ‘what we want to do’ and ‘what we are able to do’ exists across both groups and it seemed in coping with this tension further restrictions were placed on the relational opportunities available to adults with ID.

A general stance within the service was held that if basic care needs were achieved in a day that was ‘good enough’, as anything else was considered a bonus, but not an essential task. This reflects a key finding within the study of the conundrum that exists in disability services between ‘quality of care’ versus ‘quality of life’ (De Waele et al., 2005). In this study, it was found that the primary focus within the disability service was more around ‘quality of care’ and less about ‘quality of life’. This mirrors a historical legacy toward the ‘medical model’ and a need for services to provide safe and secure environments to those who are considered vulnerable.

This highlights how the construct and model of disability (see section 1.3 above), within a disability service, can shape the direction of care provided. Despite operating from person centred policies and frameworks that guide a more social model of disability (see section 1.4 above), this study has shown that disability services are not clear in how to deconstruct historical legacies of care practices, and as a result, adults with ID continue to experience imbalances of power within their relationships with care staff and disability service. This reality is risk-laden as adults with ID continue to experience unbalanced relationships between staff and the disability service. This study has shown that some adults with ID remain dependant on others, powerless and unequal partners in decision making. Confirming how the process of dehumanisation is manifest in the exercising of control and power over adults with ID (Chappell, Goodley, & Lawthorn, 2001). This reflects what Pitonyak (2014) describes as a ‘system-centred’ approach to care rather than a ‘person-centred’ approach whereby adults with ID are seen as objects to be processed by the system. Within such a system the opportunity for change does not occur relationally and instead the interests of adults with ID are often ignored (Pitonyak, 2014). This raises concern with regard to the vulnerability of adults with ID to experience abuse in residential services, as research by Hanley & Marsland (2014) has shown abuse and harm can occur where imbalances of power and control exist within the relationship between adults with ID and staff. This study highlights how adults with ID exist in the world of residential services and how their being is undoubtedly shaped by the subtle forces of staff expectations, social roles and relationships (Ryle & Kerr, 2004). Therefore, if disability services do not attend to the relational needs of adults with ID and support meaningful relationships between adults with ID and their support staff; adults with ID will remain vulnerable to abuse in disability services.

5.4. Theme 2: Challenges to delivering person-centred care

Policy development in Ireland towards person-centred care for adults with ID has been driven by the need to seek solutions to change culture in order to reduce institutional abuse and improve quality of care (HSE, 2018). While such linear processes, such as changing practices and policies, are welcome there is limited focus within the literature enquiring about those questions that deepen our understanding of the issues experienced by those living in residential services (Araten-Bergman, Bigby & Ritichie, 2017).

This study confirms previous research by Marsland, Oakes & Bright (2015) and demonstrates that there are systemic risk factors that restrict person-centeredness, which may contribute to the continued abuse of adults with ID who live in residential services. Challenges to delivering person-centred care were identified by Mansell & Beadle-Brown (2004) who argued that unless there was a shift in how disability services were funded and how staff are trained the delivery of person centred care across all adults with ID would be difficult. This is confirmed in this study, whereby funding constraints and the lack of focus on staff training to adequately support the needs of service users were identified as challenges to delivering person centred care.

For adults with ID they were most familiar with the acronym P.C.P (person centred planning), as this was the language most familiar to them. All had awareness of a ‘P.C.P meeting’ which they understood occurred every year with a broad aim to helping them decide upon their goals. For many they did not see themselves as being central to this meeting, but rather it was a place for their family members and staff to make decisions about them. This further reflects the position of ‘less than’ held by adults with ID who are in relationship with those ‘who know best’ and further confirms the dehumanising social processes that exist. It seems there is avoidance in wanting to really get to know adults with ID who live in residential services and hear what they have to say about their lives. Person-centeredness is rooted in the development of healthful relationships, but it seems that within this disability service there is resistance to relationships and a fear of getting ‘too close’ to adults with ID. This study highlights how in negotiating conflict within the relationship between staff and service users there is a tendency towards prioritising the practical sides of the job and delivering basic care versus addressing the human emotional aspects of the relationship. As a result this study has shown that there is little space for understanding the psychological realities of adults with ID and how their emotional lives need to be considered when evaluating quality of care. These results provide deeper insight into how difficult it can be for both adults with ID and staff to be in relationship and engage in a person-centred approach.

The lack of understanding of what person-centred means within this study amongst a group of adults with mild to moderate ID, demonstrates how difficult it is to support adults with ID with more severe to profound ID to understand the process, as they may not fully understand the choices and decisions being made with regard to their quality of life. This study suggests that attention should turn to the quality and role of meaningful relationships adults with ID have in their life when assessing quality of life outcomes, as opposed to the number of goals identified in a person centred plan.

For all participants person-centred planning seemed to be communicated as a paper pushing exercise, rather than, embedded as a cultural practice aimed to ensure an individual approach to living an ordinary life (Goodley, 2001). While on paper it may appear that the disability service delivered good practice in person-centred planning, this was not reflected in the lived experiences of participants. Adults with ID and staff expressed a lack of choice and individualised support generally for those living within residential services. According to Ratti et al., (2016) there remains limited research into the effectiveness of person centred care making significant changes in the quality of life of adults with ID. It is argued by Richards (2019), that it is more important to focus on the contextual factors that limit adults with ID having full control over their lives. I agree with Roberts (2019), as this study found that the quality of life of adults with ID was limited by cultural and contextual factors, such as a lack of control and power over their lives. I argue too that a person centred care framework alone will not ensure significant changes in the lives of adults with ID living in residential services. I agree with Richards (2019) and Mansell & Beadle-Brown (2004) that greater focus needs to be paid to changing the cultural and contextual factors, such as power dynamics, funding arrangements and staff training and support, if real change is to be observed within the quality of life outcomes of adults with ID living in residential services.

National policy in Ireland has undertaken a major reform of services for adults with ID entitled ‘Transforming lives’. At the heart of this reform is to support adults with ID live a life of their choosing in the community. While all the adults with ID lived in the community a dominant theme was that their lived experience was of having ‘no choice’. This was reflected in the issues expressed, such as not having choice of who they lived with, not having choice around staff employed to support them, not having choice in the location of where they lived (living in accommodation that was too far away from local amenities in the country) and loneliness due to not having enough social supports outside of staff and family.

This theme of lack of choice was shared by staff and was reflected by Breda (manager) in this statement *"it (person centeredness) can sometimes appear tokenism and that that's an issue"* (127). While adults with ID were living in homes in the community they were not exercising choice and control in their daily lives, they were not fully participating in social or civic life and had limited opportunity for meaningful personal relationships. These restrictions to social inclusion confirm research conducted by Forrester-Jones et al. (2006) who found that despite the efforts of disability services to adopt more socially inclusive environments for adults with ID, concern remains that adults with ID continue to be socially isolated and lonely, particularly when staff continue to be the main providers of emotional and practical support. This was considered by Forrester-Jones et al. (2006) to be due to relationships between staff and adults with ID being less likely reciprocal. A similar finding was identified in this study whereby staff were reluctant to get 'too close' to service users due to a lack of clarity between the personal and professional relationship. For many the relationship between adults with ID and staff is not mutually beneficial with adults with ID requiring a lot more emotionally from staff than staff seek from those adults with ID they support. This is not something that is spoken about or acknowledged within the disability service and serves to drive an on-going tension within the service about how to be in relationship with adults with ID.

While all the adults with ID experienced opportunities for setting goals, there was an expectation that change was slow and goals that would see the biggest change in their overall quality of life were unlikely to happen quickly or at all. The dominant theme around why significant change was so hard to achieve was down to budgets and financial constraints within the disability service. Adults with ID and staff expressed their frustration of not having enough money to support those who lived in residential services. Some staff expressed concern of a growing cultural stance whereby budgets and money dominated the discourse around meeting the needs of service users. This concern seemed to reflect a hierarchical position within the service whereby the need to manage money was a shared view filtering from the top of the organisation down. This concern seemed to undermine the efforts of staff in the implementation of person-centred care and took time away from the development of relationships between adults with ID and staff, which would maximise human to human connection (Schuengel, 2010). This study reveals the tension between meeting the needs of adults with ID versus meeting the organisational needs. This raises concern about whether disability services masquerade being person-centred when in reality so many adults with ID are living in controlling and dehumanising environments with barren lifestyles that few of us would choose to inhabit (Durand, 1990; Risley, 1996; Osgood, 2005).

Keeping people safe was a dominant theme and was observed across all staff interviewed regardless of their role within the service. However, it was less clear what adults with ID were being kept safe from. This attitude reflects a largely held belief within the disability service that adults with ID are vulnerable and need protecting and this focus dominates much of the decision making around their care. However, in the attempts to protect adults with ID from some real or imagined harm this paralysed any opportunity for personal growth, which could be argued, is another form of abuse.

Organisational culture is a key influencing component of person centred care. The national framework for person-cantered planning (HSE, 2018) has identified a number of beliefs and philosophies that are considered to be at the foundations of good practice; empowerment, choice, inclusion and active citizenship. This study has shown that adults with ID are not empowered, do not have choice within many aspects of their life and face many challenges to inclusion within their communities. Research by Peelo-Kilroe et al, (2017) has shown that to enhance cultures of person-centeredness there needs to be a whole system approach in order to bring about fundamental change in complex health care organisations. This requires recognition of patterns that drive thinking and behaviour. This study has demonstrated that there are cultural dimensions within the service that impede implementing person centred care and do not "give permission for adults with ID to occupy the full breadth of relational space which might ameliorate any 'organic' difficulty" (Greenhill, 2011, p. 13). This begs the question; are disability services listening and learning from the hard lessons of recent scandals of abuse and willing to face the stigmatising attitudes and beliefs held about adults with ID that continue to restrict and limit their quality of life?

5.5. Theme 3: Shared needs

This study has shown (Chapter 4) that the need for more support and training was an issue for many adults with ID and staff. In most instances the priority for training within the service was to satisfy mandatory obligations for staff employment (e.g. manual handling, fire safety). There were no on-going structured training opportunities for adults with ID within the service, again reflecting how the disability service prioritizes the meeting of organisational need over the needs of service users. Staff identified that there was need to deliver regular and on-going training opportunities for adults with ID to help support the development of important skills, such as valuable social skills training. It was also highlighted that adults with ID were not provided with enough psycho-education around difficult life experiences, such as bereavement and past experiences of trauma. Interestingly, adults with ID did not identify their need for training or up-skilling, rather their concern was a lack of support from staff and a lack of training of staff in how best to provide them with support. Again, reflecting the culture of dependence whereby adults with ID can only see themselves as needy and not capable of being effective at meeting their own needs. This suggests an internalised view of incompetence which confirms research by Dorozenko, Roberts & Bishop (2015a), whereby the cultural perspective within disability services means that adults with ID are not seen to have the capacity to be trained to meet their own needs which benefits professional interests.

Adults with ID described a difference between what made a ‘good’ staff and a ‘bad’ staff. A similar view was held by staff who described those who worked in the service who had a real passion for the work and went above and beyond their role, compared to those staff who held attitudes that were not in keeping with the values of person centeredness. Staff interviewed saw attitudes from colleagues that disempowered adults with ID and maintained an imbalance of power. It was a shared view that when it came to the employment of staff it was down to luck if you found a staff that had a genuine interest in the work.

However, the concern about whether staff were cut out for the job, or not, and seeking feedback from adults with ID regarding staff performance was not sought. Adults with ID felt that staff could do with more regular training to fully understand their role and how the job impacts upon the quality of life of those they support. Adults with ID often felt that some staff missed the fact that their job directly affected their life. For some adults with ID they experienced an attitude from staff that it is ‘just a job for them’. I was struck by how aware adults with ID were regarding the fact that staff get paid regardless of how ‘good’ or ‘bad’ a job they do. Staff and adults with ID shared a discomfort in this reality, but it was not spoken about between them. This finding reveals the significance of the relationship between adults with ID and staff, and demonstrates how service users value more the opportunity to experience meaningful relationships rather than PCP meetings to plan their lives.

Staff also expressed concern about their lack of opportunity for skill development. Some staff spoke about working with adults with ID with dual diagnosis and enduring mental health issues. Staff expressed their lack of training to better understand and provide better support to those with more complex needs. There was disparity between what is deemed to be important and a priority support and training from an organisational point of view and the experiences of adults with ID and staff. The disconnect between the needs of adults with ID, needs of staff and the needs of the service were at odds, and demonstrates the complexity and multi-dimensional competing needs within the disability service.

In summary, the main themes which emerged from this study were common across the two participant groups, adults with ID and staff. The groups reflected the complexities of life in residential services and the difficulties in working to the principals of the social model of disability and implement person-centred care, which are vital to underpin changes in power and power relationships between adults with ID, support staff and the disability service, as a means of safeguarding against abuse in disability services.

Due to these issues and despite efforts to implement person centred care, what prevailed was an organisational culture driven by values, norms and beliefs which were more aligned with the medical model of disability. Adults with ID were largely positioned as vulnerable or ‘less than’ with limited opportunity to take control of their lives; as the focus of the disability service was more about ensuring a system centred approach towards ‘quality of care’ and less about a person centred approach towards ‘quality of life’. In the next section, I address the main themes in relation to the objectives of this study.

5.6. What do the findings mean?

The qualities of community living and support for adults with ID living in residential services are often studied by examining the experiences of others without including the experiences of adults with ID (Beail & Williams, 2014). The aim of this study was to explore the experiences of adults with ID who live in residential services, and staff, of the social processes that impact upon person-centeredness in disability services, and discover what their subjective experiences can tell us about 1) the relational and cultural dynamics that exist in disability services and 2) their impact upon the quality of life of adults with ID who live in residential services. In the next section, I address the over-arching themes in relation to the research objectives of this study (as outlined in section 5.0 above).

5.7. Objective 1: Explore the nature of the relationship between adults with ID and staff.

This study demonstrates that adults with ID experienced living in residential services as fundamental to their survival and the relationships that they develop with staff predict their quality of life. Adults with ID experienced staff as significant figures in their lives, and many, were fully dependent upon them to meet their needs. The relationship between adults with ID and staff is complex and the boundaries between the personal and professional were often blurred. The organisational culture defined the roles of staff and adults with ID. The data which emerged suggests that those adults with ID living in residential services were experienced as ‘vulnerable’ and staff were experienced as the ‘protectors/minders’ with whom adults with ID depend upon. All participants understood this relationship to be significant in meeting the needs of those adults with ID living in residential services. Through interviewing both groups, it became evident that there was a conflict in what is understood about the relationship between adults with ID and staff, and the role each plays within the relational dynamic.

It was highlighted within this study that there is ambiguity with regard to the aim of the service, and what it means to provide person centred care. This confusion was impacted upon by the cultures which exist within the service which constructed a relationship with adults with ID from a position of vulnerability and led to a disavowal of real human needs.

This study demonstrates that adults with ID living in community based residential services experienced a lack of choice and control over their lives. Their relationships with staff and the disability service were not experienced as collaborative. Adults with ID experienced an imbalance of power in terms of decision making. This position of power was defined by the role adults with ID had within the organisational culture. Through documenting and analysing their experiences it became evident that adults with ID living in community residential services held the role of the ‘vulnerable one’ and relied fully on staff to meet their needs.

5.7.1. The importance of the relationship between service users and staff

Literature suggests that the provision of community based residential services for adults with ID provides for better quality of care outcomes for adults with ID, particularly those with more severe and complex needs (Bredewold, Hermus & Trappenburg, 2020). However, much of the research evaluating outcomes focuses on objective life conditions of adults with ID with far less evidence available accounting for the subjective experiences of adults with ID (Perry & Felce, 2003). The research suggests that there is marked variation in both the processes that underlie service delivery and outcomes experienced by residents (Emerson & Hatton, 1994). What is clear within the research is that often it is the quality of support received by adults with ID living in community residential services that predicts better quality of life outcomes (Beadle-Brown, Hutchinson & Whelton, 2008). This was confirmed in the current study whereby adults with ID see staff as being key players in enhancing their quality of life. In particular, adults with ID valued the quality of the interpersonal relationship with staff and the ability of staff to really get to know them. This confirms the research by Schuengel et al. (2010) who highlight relationships with care staff plays a significant role in determining quality of care for adults with ID living in residential services.

However, staff experienced great conflict regarding the limitations and boundaries of this relationship. Staff struggled with the tension between engaging in real human to human contact, while also trying to protect professional boundaries. This lack of clarity regarding the relationship between staff and adults with ID is an area that requires further exploration and understanding within the service. This has been highlighted in research previously. Antaki, Finlay & Walton (2007) reported that adults with ID perceive support staff at the centre of their social support networks and friendships. Tinney, Forde, Hone, Flanagan & Smith (2015) reported in their study how some adults with ID were upset to learn that staff employed to provide support were not their ‘friends’. In this study, there was evidence of how tricky it was to navigate this relationship and how complex an issue it was for both adults with ID and staff to resolve, reflecting the need for greater consideration of this social relationship.

This dependence and need on the quality of this relationship is pivotal in meeting the needs of those living in residential services and highlights the dyadic nature of professional support in residential services. Adults with ID seem to favour those staff who engage in an interpersonal relationship with them and are more attuned and sensitive to their needs. This was reflected in how adults with

ID differentiated between the “good” and “bad” staff. “Good staff” were described as those who take time to really get to know you whereas “bad” staff were considered those who did not develop a close bond with adults with ID. This confirms research by Reinders (2010) who identified how staff’s awareness of the specific particularities of an adult with ID is crucial for quality of care. This calls for staff to see beyond an individual’s disability and see the person.

Clegg & Lansdall-Welfare (1995) first recognised the value of an attachment relationship for the care of adults with ID (Schuengel et al, 2010). Their research suggests that adults with ID living in residential services are predisposed toward developing an attachment relationship with care staff. Adults with ID in this study provided glimpses of the closeness of their emotional attachment to staff when they describe their experiences of how they felt the loss of this relationship when staff left. Adults with ID describe the shock and the overwhelming loss and how significant it was for them to have someone in their lives, who knew them so well, was nice and caring. I interpreted this as adults with ID experiencing what it means to be seen and feel a real human connection. However, staff were more conflicted and anxious about allowing for *dependency* and real human connection. It seemed managing this conflict was in the hands of staff who exercised more power and control about how the relationship between service users and staff should be constructed. Staff describe their efforts to ensure that emotional distance is maintained in this relationship by ensuring staffing rosters were rotated. This seemed to occur without consultation or collaboration with service users. Staff appeared to adopt a ‘*we know best’* approach to managing this relationship. The assumption was that adults with ID would not tolerate the loss of this relationship and so it was best to avoid any closeness occurring in the first place. This reflects an anxiety held about adults with ID and their ability to experience and manage heightened emotion. This reflects similar findings in the study by Dorozenko, Roberts & Bishop (2015a) whereby adults with ID can experience assumptions of incompetence which can limit adults with ID as being seen as ‘normal’ and functional ‘human beings’. Such attitudes reinforce the orientation to see the pathological and maladaptive behaviours rather than seeing the resilient and ordinary lives of adults with ID (Nunkoosing, 2019).

This highlights how the emotional security and well-being of adults with ID is dependent upon their relationships with staff and raises the importance of paying more systemic attention to the relational needs of adults with ID in the field and the impact of professional-power knowledge upon them.

5.8. Objective 2: Identify factors that impact upon person-centeredness in residential services.

This study has revealed that there are challenges to delivering person centred care within this disability service. Both groups shared the experience that a lack of time and resources significantly restricted the choices of many adults with ID who live in residential services. Both groups also spoke about the pressure of staff and how difficult it was for them to provide person centred support to adults with ID. As a result of these challenges, the disability service was unable to meet the needs of many adults with ID. The greatest challenge expressed by staff in delivering person centred care was the immense pressure they experienced from both the organisational context and culture and the interpersonal contact with adults with ID. Staff experienced a pull from the organisation to provide objective measurements regarding quality of care and a pull from adults with ID to meet their subjective needs in fulfilment of their quality of life. This pull in opposite directions left staff feeling disempowered and disabled in their roles within the service. The consequence of this was the development of disabling attitudes that saw the job of providing care to adults with ID as an ‘impossible task’ and a dilution of expectation, whereby ‘care’ was reduced to ensure basic needs were met and anything else was seen as a bonus. This study demonstrates how the expectations of the quality of care provided to adults with ID can become de-valued whereby the emphasis is in addressing practical needs rather than on ensuring all adults with ID are enabled to live a ‘normal’ life (Bredewold, Hermus & Trappenburg, 2020).

5.8.1. The need to challenge attitudes which construct adults with ID as 'other'

The abuse of adults with ID who live in residential services occurs within a specific cultural and environmental context (Robinson, 2013). Within the literature (Bigby et al., 2012; Clement & Bigby, 2010; Felce, Lowe & Jones, 2002) there have been many variables identified as to why abuse is more likely to occur in residential services. Of these, organisational culture and the imbalance of power which positions adults with ID as 'other' has been the most commonly identified factor (DOH, 2012; HSE, 2016). Research by Mansell & Beadle-Brown, (2010) suggests that despite progress towards de-institutionalisation and person-centred models of care disablist attitudes can exist in community based service settings and alone these changes in service delivery are not protective factors in safeguarding adults with ID from abuse. This study confirms the concerns raised by Mansell & Beadle-Brown (2010) by identifying disabling attitudes that constructed adults with ID in this service as 'other'. Of concern was the finding that staff found it difficult to challenge such attitudes. Staff highlight how such attitudes are *passed down* and it can be difficult for new staff entering into the system to challenge these subtle forces that can limit and further restrict the choices available to adults with ID living in residential services. Within this service as a result of such disabling attitudes and prejudices which constructed adults with ID as 'vulnerable' and 'different' this provided justification for diminishing expectations for how care was provided within the service. This lowering of expectation as outlined by Claire (staff) when she said –

> "…we take really good care of people, and we do our best day-to-day, and we do a really good job of doing that…but more and more we can't do anything outside of that" (830-832).

This attitude seemed to reflect a sense of hopelessness about the outcome of support and reflects what Nunkoosing (2019) defines as "the problem of the disablement" of adults with ID lies in the attitudes of staff working within the disability field and the lack of hopefulness we hold about our work. The challenge with feeling hopeless is that adults with ID are devalued and at risk of being treated as ‘other’ and it is this attitude that we need to become more aware of and change within disability services.

This study found that in positioning adults with ID as ‘other’ created distance in the relationship between service users and staff particularly when relationships between staff and service users ended as it seemed little space was given for the ‘normal’ emotions of loss instead emotions seemed to be dismissed or disavowed. I was impacted when a staff member reflected in her interview how her manager advised her to not be upset, as it was ‘just a job’, when a service user she had grown to care about over ten years passed away. Such emotion was dismissed, diminishing the significance of the relationships that are experienced, and suggests a cultural view that it should not matter when an adult with ID dies. This disregard for the significance of the relationship reflects the dimensions of culture identified in Bigby et al (2012) research where adults with ID living in care are seen as ‘other’. This ‘otherness’ and being seen as ‘less than human’ is a concerning indicator about the position adults with ID hold within the service. There is a risk that being seen as ‘less than’ can enable abusive practices to develop, as this position can give rise to attitudes that dehumanise adults with ID (White et al., 2003).

This example further reflects the tension experienced by staff and the pull between adhering to organisational culture and human nature to engage in a real relationship with adults with ID. Having to ignore the interpersonal relationship seemed at odds with the human nature of the role of staff who are in such close contact with adults with ID every day. It was understandable therefore, in an effort to cope with this tension staff expressed having “no time” as justification to being unable to focus on the relationship with adults with ID, such was the increased demand of completing paperwork.

The discourse around having no time due to paperwork was reflected across both groups. Both staff and adults with ID reflected how an increase in ‘paperwork’ took time away from staff being able to engage with adults with ID in a way that reflected a more person centred approach. The increased demand for documentation seemed to reflect the changes overtime in safeguarding procedures and the need to provide a paper trail to prove that adults with ID were being cared for in line with current policy and best practice. The irony however, was this effort was taking time away from the relationship between staff and adults with ID and was pushing services further away from delivering person centred care. For example, as reported by Katy (Staff) who was working in the service more than 18 years. She described how the focus of the role of staff had changed considerably since she began to work there. While she acknowledged some of the improvements, her greatest concern, was how the trend toward completed paperwork was valued more by management than quality time spent with the adults with ID she supported.

Schuengel at al. (2010) highlighted in their research that a lack of human to human connection means for those adults with ID living in residential services there is potential for a lack of fulfilment of their attachment needs and attuned sensitive care. This was reflected in this research whereby staff acknowledged that adults with ID had emotional needs that needed to be fulfilled, but such were the demands upon them it seemed that addressing adults with ID's emotional and psychological needs was too much for staff to think about. The broad view was that there were multiple and diverse demands placed upon staff which limited their opportunity to understand their role within the service and in relationship with adults with ID with any real clarity. This further reflected the complexity of the relationship between cultural and organisational factors, and how the wider culture of the disability service, the specific care environment, and the relationship between staff and adults with ID are interwoven and need to be understood, in order to promote real cultural and social change in disability services and eliminate the risk of abusive practices developing.

The current research findings propose the possibility that adults with ID stand to benefit from greater consideration, by professionals, of the contexts in which they live, particularly the relational system. Most importantly this study highlights the importance of professionals working with adults with ID to be aware of the presence and influence of attitudes that stigmatise and discount the lived experience of the men and women we are paid to support.

5.9. Objective 3: Explore the nature of organisational culture in disability services and its impact upon the quality of life of adults with ID who live in residential services.

This study highlights how the organisational culture and the given identity of adults with ID, as ‘vulnerable’, impacts the quality of the relationship between adults with ID and staff, and thereby, impacts upon the quality of life of adults with ID who live in community based residential services. This position of being seen as vulnerable set up adults with ID as being seen as unable to make decisions or have control or power over their lives.

5.9.1. Systemic risk factors that impact the lives of adults with ID in residential services

The misalignment of power and control of adults with ID living in residential services was identified within the research by Bigby et al. (2012) as a dimension of culture within underperforming residential services for adults with ID. This research confirmed a lack of power and control within the lives of those adults, who participated in the study, and a perception that adults with ID were absent in many decision making processes. In the current research, it was observed that financial constraints were perceived to dictate many of the decisions made regarding the lives of adults with ID living in residential services, suggesting the wider social and political context that dictates the provision of care in the Republic of Ireland.

In the literature, regarding quality of care for adults with ID living in residential services, a lack of power and control has been shown to be a factor in the development of poor and abusive care practices (White et al., 2003). In the current research, it was perceived that the power of decision making about the lives of adults with ID was in the hands of higher management. The study identified that for some adults with ID living in community based residential services did not provide them with a greater sense of control or power over their lives and compromised their quality of life. For example, adults with ID experienced having no say in where or with whom they live, no choice regarding staffing and restricted choice to engage socially in their local community. The evidence of restricted choices in residential services, in this disability service, reflects the challenges of living in community residential services. The adults with ID interviewed did not have access to individualised funding. Clearly, in the Republic of Ireland the aim of delivering personalised budgets and developing person centred care services has a long way to go.

Staff too felt powerless within the system as advocates for those adults with ID they supported. For example, Katy (staff) reported how a manager approached an adult with ID about moving to a new residential house. The decision for the move was to make way for someone else and less about meeting the needs of the individual who was being asked to leave the place she knew as home for many years. This process seems to cause conflict between staff and management and undermines the role staff have as advocates for those they support. This assertion of power and control by management contradicts what staff are being asked to do and undermines what is outlined in the services policies and procedures regarding person-centeredness. This misalignment in ‘what we say we do’ and ‘what we actually do’ leads to confusion and increases the risk of staff stress (Bigby et al., 2012). Staff stress has been documented in the existing literature in ID, particularly with regard to its affect upon the quality of services for adults with ID (Hatton et al., 2001). In the current research, it was noted that staff were stressed and were overwhelmed with the increased demands upon them and their felt sense that providing support to adults with ID was an ‘impossible task’.

The discourse around ‘impossibility’ seemed to reflect a construct within the service of ‘*not able*’; adults with ID were ‘*not able*’ to make choices, staff were ‘*not able*’ to provide support in a manner they would have liked and management were ‘*not able*’ to deliver on individualised choices due to funding constraints. This positioning seemed to keep all parties involved in the lives of adults with ID ‘disabled’ with an overwhelming sense of a ‘lack of power and control’. The seeming lack of control, which weaved throughout the hierarchical system, seemed to be projected in a culture that diminished the role of adults with ID and prevented opportunities for collaboration and reciprocity. Thus, maintaining power imbalances that inhibited real change and true person-centeredness.

In summary, research suggests that person centred care enables adults with ID who live in residential services take control of their lives, thereby improving their quality of life and well-being (HSE, 2018; Robertson et al., 2007). However, such research underestimates the impact of cultural misconceptions within disability services of what ‘care’ means for those who carry the label of ‘ID’. In this study, I explore the experiences of six adults with ID who live in residential services and six staff employed within the disability service. I highlight the complexity of this relationship within the context of the organisational setting and its impact upon the quality of life of adults with ID. I argue, that unless staff at all levels working within a disability service engage in dialogues, and begin to mutually explore the cultural dimensions that create imbalances of power, then this failure could see the continued abuse of adults with ID living in residential services.

5.10. Conclusion

At the beginning of this research, I was concerned that there was little evidence about the experiences of adults with ID and staff of the social processes that impact upon person-centeredness in residential services. This study has shown that it is not enough to have a system of quality of care guided by the principles of person centeredness alone to ensure the best possible quality of life for adults with ID. Rather, consideration of the cultural and contextual factors that impact upon the relationships held by adults with ID needs to be built into the values and practices of services offered to adults with ID.

Chapter 6. CONCLUSION

6.1. Chapter outline

In this concluding chapter I will briefly discuss the key findings. The implications of this study's results are explored in relation to providing person centred care for adults with ID in the Republic of Ireland. The strengths and limitations of the study are then identified, with specific focus on the implications of a qualitative approach. Finally, the chapter concludes with implications for future practice and the role of Counselling Psychologists within the field of ID, along with my reflections on my own journey, as the researcher, and as a Counselling Psychologist and Psychotherapist in relationship with adults with ID, staff and the disability service.

6.2. Key Findings

This study set out to explore the experiences of adults with ID who live in residential services, and staff, of social processes that impact upon person-centeredness, and discover what their experiences tell us about the relational and cultural dynamics that exist in disability services in the Republic of Ireland, and their impact upon the quality of life of adults with ID who live in residential services.

Through the findings, as outlined below, this study has highlighted the complex and multi-dimensional issues of living in residential services for adults with ID. This study proposes that adults with ID remain at risk of experiencing poor and abusive care practices unless greater attention is paid to the cultural and contextual factors that impact upon the relationships held by adults with ID and built into the values and practices of services offered to them. The three most common issues across both participant groups which address the research aim above are;

1. Within this disability service it was found that there is ambiguity with regard to the aim of the disability service and what it means to provide person centred care. As a result, a tension exists between achieving 'quality of care' versus 'quality of life' outcomes. Despite operating from person centred policies and frameworks; this study has found that

within this disability service there is a lack of clarity in how to deconstruct historical legacies of care, such as the medical model of disability. This study has shown that adults with ID continue to experience stigma whereby they are viewed as vulnerable, incompetent and not quite human (Dorozenko, Roberts & Bishop, 2015b). This suggests that in order to enhance person centred cultures there needs to be a whole system approach toward change with greater awareness brought to the patterns that drive thinking and behaviour within disability services.

2. It was confirmed in the current study that adults with ID see staff as key players in enhancing their quality of life. Adults with ID value the interpersonal relationship with staff and the ability of staff to really get to know them. Adults with ID favoured those staff who were more attuned and sensitive to their needs. However, staff experienced a tension between the personal and professional relationship and saw the task of being in relationship with adults with ID as an 'impossible task'. This resulted in a distancing from the relationship and a dilution of expectation, whereby 'care' was reduced to simply meeting the basic needs of adults with ID. This left some adults with ID with many unmet emotional and social needs. This suggests the need to raise awareness of paying more systemic attention to the relational needs of adults with ID who live in residential services.
3. This study highlights how adults with ID exist in the world of residential services and how their being is undoubtedly shaped by the subtle forces of staff expectations, social roles and relationships (Ryle & Kerr, 2004). This study found that the quality of life of adults with ID was limited by cultural and contextual factors, such as a lack of control and power over their lives. This study proposes that unless disability services engage in dialogues and explore the cultural dimensions that create imbalances of power, then this failure could see the continued abuse of adults with ID living in residential services.

6.3. Contribution and recommendations

This study explored the experiences of adults with ID living in community based residential services in the Republic of Ireland from the dual perspective of adults with ID and staff. Choosing this novel approach has meant the addition of new knowledge into the field of intellectual disabilities on the issues that affect the relational dynamics between adults with ID and staff, and the impact of context and culture on the provision of person centred care to adults with ID. This new knowledge has value in informing psychological, social care and health practices and in the development of policies that guide models of support for adults with ID living in residential services.

In addition, there is potential for disability services to reflect upon and improve the processes of service delivery and the cultures that exist within the service that impact upon the quality of life and well-being of adults with ID and safeguard against poor and abusive practices developing.

The participant voices in this study need to be heard, to move on policies that drive thinking and behaviour toward the measurable and objective outcomes of quality of care, to developing policies that allow for relational ways of working with adults with ID. Whereby, measurement of quality of life outcomes relies on the implicit subjective experiences of real human contact and connection between adults with ID and their supporters.

As a Counselling Psychologist and Psychotherapist working within the field of ID, this research has made me reflect on how I understand disability and care in the field of ID. I have also reflected on my relationship with adults with ID and staff in disability services and the role of power within this dynamic. Often in my experience psychologists are given a lot of power to ‘fix and solve’ the presenting issues. However, this study has given me great insight into how adults with ID experience their supports and has enabled me to use this knowledge in my work. Particularly, I have re-evaluated how I, as a psychologist, enable imbalances of power between staff teams and adults with ID by often seeking greater information about the client's presenting problem from the staff team or family, rather than, in collaboration with the adult with ID. Prior to this study my interaction with many clients presenting with an ID referred for psychological intervention would involve observing the adult with ID in their environment rather than engaging in a relationship with them and seeking to understand their experience of the relationships around them.

I will use the knowledge gained from this study in my current practice to;

- Develop reflective practice sessions for staff teams.
- Develop a protocol for debriefing following incidents of challenging behaviour which has a relational focus.
- Develop a protocol for managing loss and endings in the lives of adults with ID.
- Develop training to frontline staff on working relationally with adults with ID incorporating relational, developmental, attachment and trauma-informed theory and practice.
- Develop psycho-education workshops for adults with ID around topics such as; bereavement, loss and endings and understanding anxiety.

In my experience, working in the Republic of Ireland and training in the UK, Counselling Psychologists and Psychotherapists, both trainee and trained, have had little training on working with adults with ID and with disability services. However, this study proposes that the practice of Counselling Psychology should endeavour to engage more and broaden our position on working with and supporting men and women who are labelled with an 'intellectual disability'. A strength of our profession is to work within a 'relational framework' and uphold an overarching critical and pluralist philosophical perspective towards the construction of knowledge which enables us to hold a 'both and' perspective whereby we can validate or find 'truth' in each position even if dialectically opposed (BPS, 2018). While many psychologists may work within a 'relational framework' it may not be explicitly identified or discussed therefore in the context of this study and its findings this study argues for the idea of working relationally to be at the centre of the work in order to more fully acknowledge how processes such as power and oppression play out in the relationships available to adults with ID living in residential services. In order to further promote the possible value of this way of working and to encourage the profession of Counselling Psychology working within the field of ID. I aim to write a paper and provide seminars to Counselling Psychologists and Psychotherapists with regard to working with adults with ID to hopefully support colleagues and other professionals learn from my experience and consider developing their practices to include working with adults with ID. The study achieved an insight into the complex multi-dimensional issues that can impact upon the relational dynamics that exist for adults with ID, particularly, the imbalances of power and control they experience over their lives. It is significant for psychological practitioners to understand the contextual and social position of adults with ID living in residential services, so that Psychologists may help to lead transforming care and support for adults with ID to ensure their well-being through the promotion of meaningful relationships.

6.4. Implementation of the findings

In considering the contribution this study makes, and the use, I intend to make of it in my own practice; I have developed a number of suggested recommendations for disability services. The recommendations capture the need for greater awareness of working relationally with adults with ID, staff and disability services. The recommendations suggest actions to be taken and the rationale for implementing same that may also further support the development of policies in the future.

6.4.1. Recommendations

Table 5 (below) summarises the recommendations in order to introduce working relationally with adults with ID and the support networks around them. In a disability service there needs to be recognition of this need that informs policy and practice. The policy needs to acknowledge the existence of 1) the relational needs of adults with ID and the intentional use of the relationship they develop with their support networks to ensure the development of emotional security and 2) provide procedures for the training and supervision of staff, including management, that expand the skills of staff to professionally embody the relationships they maintain with adults with ID they support.

Table 5 Recommendations for disability services and counselling psychologists and psychotherapists

Recommendations for disability services and counselling psychologists and psychotherapists

	Disability Service	Psychologist/psychological therapist
Acknowledgment	Existence of cultures and attitudes that: • Impact upon the quality of life of adults with ID • Impact upon the quality of support provided by staff to adults with ID • Impact upon the implementation of policies and person centred practices	Existence of cultures and attitudes that: • Impact upon the quality of life of adults with ID • Impact upon the quality of support provided by staff to adults with ID • Impact upon the implementation of policies and person centred practices
Actions	• Develop policy for working relationally with adults with ID • Develop protocols for delivering support • Auditing/Evaluating quality of life outcomes • Reflective practice • Training	• Develop awareness of service needs • Search for literature, CPD training to better inform formulation, clinical interventions, skills • Reflect on own practice • Use of supervision

	Disability Service	Psychologist/psychological therapist
		• Develop training for staff • Facilitate reflective practice
Rationale	• Improve quality of life of adults with ID • Improve quality of support delivered by staff and disability services • Need for cultural shift • Reduce risk of poor and abusive practices developing	• Enhance practice working with adults with ID and systems

6.5. Strengths and future research

This study provides an understanding of the experiences of adults with ID and staff of the social processes that impact upon person-centeredness in one disability service in the Republic of Ireland. Knowledge gained through this study suggests that having a system of quality of care guided by the principles of person centeredness alone will not ensure the best possible quality of life for adults with ID, nor does it offer adults with ID any greater protection from poor or abusive care practices developing in disability services. This study has shown that there are dimensions of cultures that exist in residential services that influence staff and organisational practices and restrict adults with ID who live in residential services from receiving person centred care. The findings show that there is merit in introducing practices that invite dialogues through reflection on the social processes such as; dehumanisation, that exist in disability services which may promote the voices and interests of adults with ID living in residential services and support a more radical cultural shift (Witso & Hauger, 2020).

The current research highlights a number of exciting areas that warrant exploration in the development of research for working with adults with ID who live in residential services. First, the findings indicate a need to build upon this specific study and explore the identified research objectives using a more representative sample and method by encompassing an organisation wide study across the island of Ireland. A greater understanding of the factors that contribute to attitudes and culture that maintain imbalances of power and control in relation to delivering support to adults with ID is warranted, if we are to understand how to cultivate more radical shifts in attitudes towards adults with ID. Second, it is notable that the current research focused on individuals with mild to moderate ID. Future studies should explore the experiences of adults with more severe to profound levels of ID. Thirdly, the study did not focus on the experience of the relationship between adults with ID and their direct support staff. Research that focuses specifically on the dyadic relationship between pairs of adults with ID and staff would produce a more in-depth exploration of new insights of this relationship.

A final and perhaps more equivocating issue that was raised in the current study is the issue of collaboration and the need for more participatory research with adults with ID, whereby the power to explore the issues that most affect their lives is handed to them, so that adults with ID may play an active and influential part in the decisions that affect their life.

6.6. Methodological benefits and limitations

This research revealed that a phenomenological study and using thematic analysis across groups living and working in a disability service was suitable in identifying the complexity of everyday life for adults with ID living in residential services. This study gives a valuable contribution to the growing body of qualitative studies highlighting the voices of adults with ID when it comes to everyday life and the complexities and shortcomings of a life in residential services (Bond & Hurst, 2010; Haigh et al, 2013). Furthermore, this exploratory study demonstrates how the use of a qualitative approach is ideal for exploring in-depth under-researched topics and provides the context for future studies with more generalizable focus. Conversely, the main disadvantage of this qualitative approach and the most apparent limitation was the small scale of this study. This study only sought the experiences of participants from one disability service in the Republic of Ireland, and therefore, findings cannot be extended across all disability services or to wider populations. This study focused on exploring an under researched area in an effort to propose a new understanding of delivering person centred care in residential services, as a safeguard against abuse, rather than to test whether the results were statistically significant or due to chance.

This study does not propose that all adults with ID who live in residential services are restricted from living a life of their choosing or will experience abuse in residential services. Rather, this study sought to interview adults with ID who are currently living in residential services, and staff who are currently employed by the same disability service, in order to explicate an understanding of the social processes involved that may impact upon the quality of life of adults with ID and may increase the risk of poor and abusive care practices developing. This study did not seek to explore individual's experience of abuse, as the study was focused on gaining a nuanced perspective from both adults with ID and staff on the relational and systemic aspects of care, in order to develop an understanding of the wider context of the cultural dimensions that exist within the disability service. This was an intentional recruitment decision in order to fill the gap in the current literature.

6.7. Personal Reflections

When I started my research journey I held a set of beliefs and values about what it means to be a Counselling Psychologist and Psychotherapist working with adults with ID which relate to my own personal and professional experiences. I held my own assumptions regarding what it means to have an intellectual disability, what it means to live in residential services and what it means to be seen as vulnerable to abuse. I also had my own views regarding the perspective of power in relationships with others particularly, in the role of psychologist. I understood from the research that a lack of power and control in the lives of adults with ID is a risk factor for abuse, and I was curious to understand if similar social processes exist within community residential services where the system of care is guided by principles of person-centeredness.

I was struck by how ‘disabled’ adults with ID and staff appeared to be with regard to challenging the imbalances of power and control they experience despite the awareness that this has an impact upon the quality of life outcomes for adults with ID within the service. I was saddened by their view that they have no control or power to change this reality – that it is a given. My research has shown the need for more psychological support for adults with ID and their support networks that focus on addressing the systemic issues that exist within disability services. Often the work of psychologists, based on my own experience, is to address an issue or problem that is acted out through behaviours of concern without consideration or focus on the cultural and relational issues that surround, within, and between people. The knowledge and understanding that I have gained from this study has helped me to appreciate further the complexity of the lives of adults with ID who live in residential services and the impact cultures and attitudes of others have on shaping their lives.

What I have learned and understand now is what it means to work in collaboration with adults with ID and be a professional advocate who can recognise and challenge care that is not provided in accordance with the beliefs and values of person-centeredness. As I have found my authoritative stance in relation to my research study, so too have I in parallel found my authoritative stance, as a Counselling Psychologist and Psychotherapist in the field of ID.

6.8. Conclusion

Although several studies demonstrate that smaller community based residential services achieve better quality of life outcomes on multiple levels for some adults with ID, the move to community living in itself cannot guarantee that adults with ID will realize a quality of life associated with social inclusion, participation and a life of one’s own (Mansell, 2005; Stancliffe, Abery & Smith, 2000). Factors associated with poor outcomes for adults with ID living in community residential services include; the co-location of residential services in a form of organization which tends to recreate aspects of institutional culture (Bigby et al., 2012) and the critical role staff and disability services play in achieving quality of life outcomes for adults with ID living in residential services through the way they provide support (Hastings, 2010; Mansell & Beadle-Brown, 2012; Bigby & Beadle-Brown, 2016a).

Within this study participants describe the challenges they face and the tension that exists in meeting the needs of adults with ID within a constrained system. They highlight the limited power and control adults with ID living in residential services have over their lives. This contradicts the guiding philosophies and frameworks aimed at delivering person centred care for all who live in residential services in the Republic of Ireland (HSE, 2018).

Such is the overwhelming complexity of providing support to adults with ID in a disability service it seemed that in response to the ‘impossible task’ there was an over simplification of roles whereby adults with ID were seen as ‘vulnerable’ requiring the ‘protection’ of staff. This reflects a culture within the service toward safeguarding and protecting adults with ID without considering the disabling effect such a narrow focus has on their quality of life. The dominant outlook within the service toward ensuring good ‘quality of care’ as opposed to enhancing good ‘quality of life’ ensured that adults with ID within the service were well ‘cared for’ but had limited opportunity to experience being ‘cared about’ (Reeve, 2014). This position limited any opportunity to reflect upon the intersubjective space that existed within, and between, adults with ID and their support networks, such was the influence of the wider cultural system. This is relevant to the position of Counselling Psychology within the field of ID, as it is a strength of the profession to negotiate between the “ideas, beliefs and views of a person with intellectual disabilities and synthesising the view of the wider system of support and beyond” (BPS, 2018, p.22-23), so that we understand people in context in support of real transformative change within the lives of adults with ID who live in residential services. It is my hope that my research may contribute to finding a new understanding where the “rules about intellectual disability can bend, evolve and be challenged” (Jones, 2019, p. 285).

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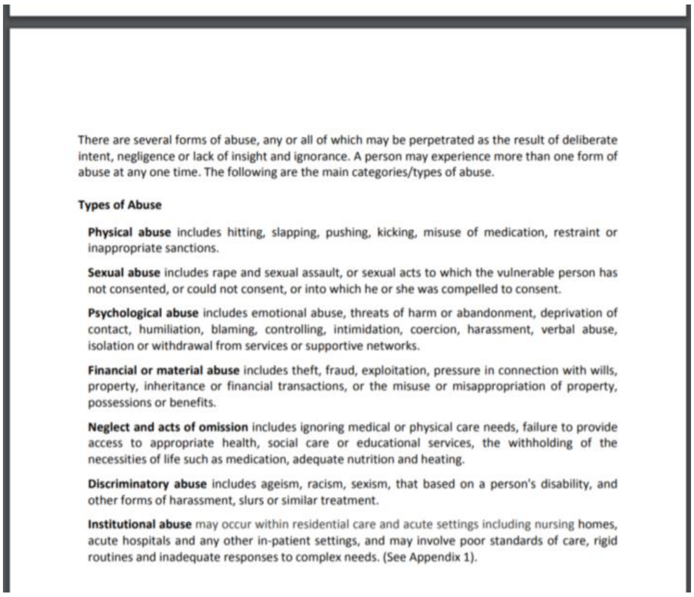
APPENDICES

Appendix A: Abuse Definitions



There are several forms of abuse, any or all of which may be perpetrated as the result of deliberate intent, negligence or lack of insight and ignorance. A person may experience more than one form of abuse at any one time. The following are the main categories/types of abuse.

Types of Abuse

Physical abuse includes hitting, slapping, pushing, kicking, misuse of medication, restraint or inappropriate sanctions.

Sexual abuse includes rape and sexual assault, or sexual acts to which the vulnerable person has not consented, or could not consent, or into which he or she was compelled to consent.

Psychological abuse includes emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks.

Financial or material abuse includes theft, fraud, exploitation, pressure in connection with wills, property, inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits.

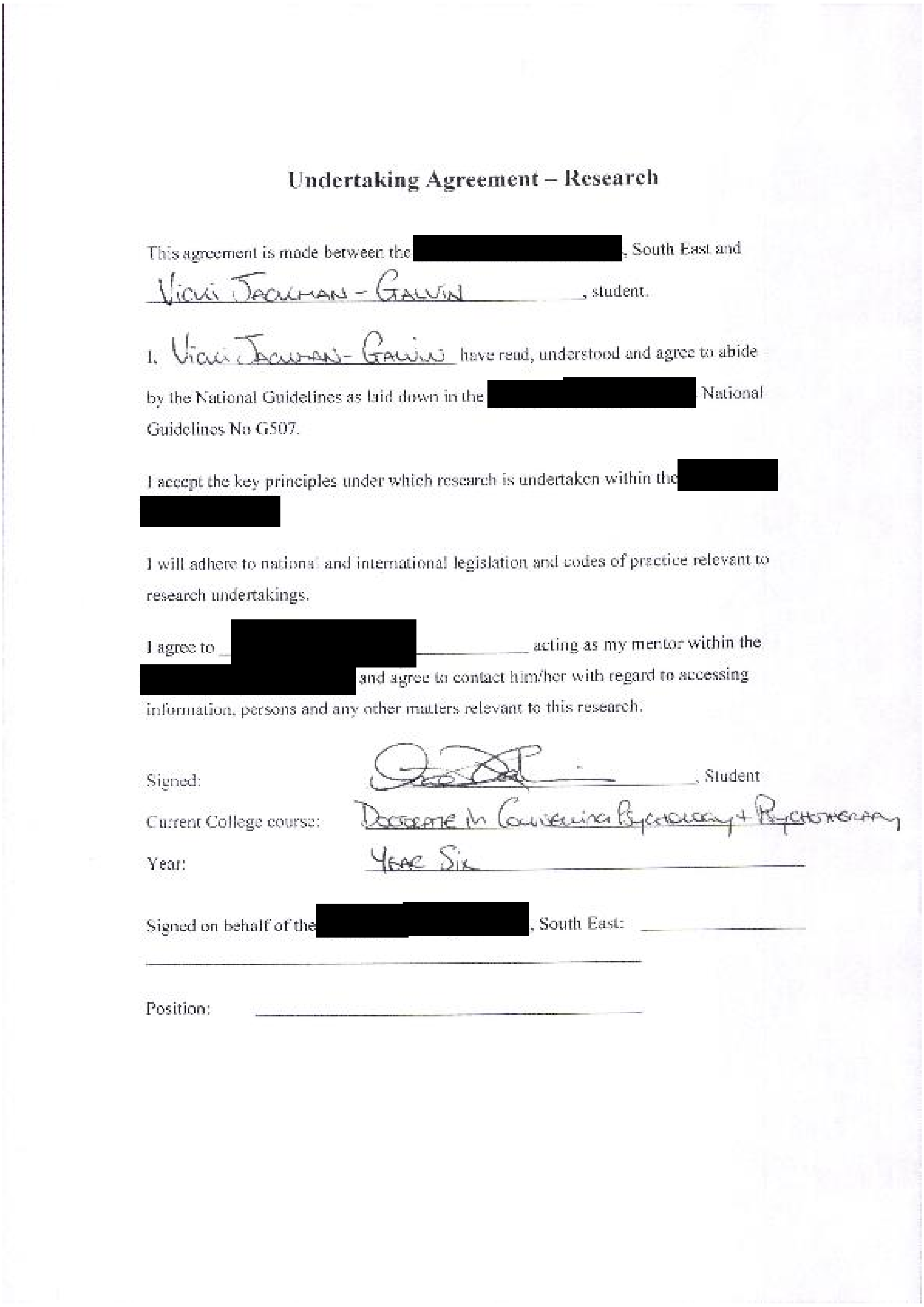
Neglect and acts of omission includes ignoring medical or physical care needs, failure to provide access to appropriate health, social care or educational services, the withholding of the necessities of life such as medication, adequate nutrition and heating.

Discriminatory abuse includes ageism, racism, sexism, that based on a person's disability, and other forms of harassment, slurs or similar treatment.

Institutional abuse may occur within residential care and acute settings including nursing homes, acute hospitals and any other in-patient settings, and may involve poor standards of care, rigid routines and inadequate responses to complex needs. (See Appendix 1).

(HSE, 2014)

Appendix B: Research Undertaking Agreement (redacted to protect participant confidentiality)



Undertaking Agreement – Research

This agreement is made between the [redacted], South East and

Vicki Jackman - Galvin ______________, student.

I, Vicki Jackman - Galvin have read, understood and agree to abide by the National Guidelines as laid down in the [redacted] National Guidelines No G507.

I accept the key principles under which research is undertaken within the [redacted]

I will adhere to national and international legislation and codes of practice relevant to research undertakings.

I agree to [redacted] ____________ acting as my mentor within the [redacted] and agree to contact him/her with regard to accessing information, persons and any other matters relevant to this research.

Signed: ______________, Student

Current College course: Doctorate in Counselling Psychology + Psychotherapy

Year: Year Six

Signed on behalf of the [redacted], South East: ______________

____

Position: ______________________________

Appendix C: Letter of approval to conduct research in disability service (redacted to protect participant confidentiality)

[redacted]

10 November 2017

Ms. Vicki Jackman- Galvin,
9 Elm Park,
[redacted]

Re: Request for recruitment in a Doctoral Research Study

Dear Vicki,

Thank you for the information submitted regarding your proposed research.

I attach Undertaking Agreement which I would ask you to sign. [redacted] has agreed to act as your mentor with regard to accessing information, persons and any other matters relevant to this research and I trust that you will find same in order.

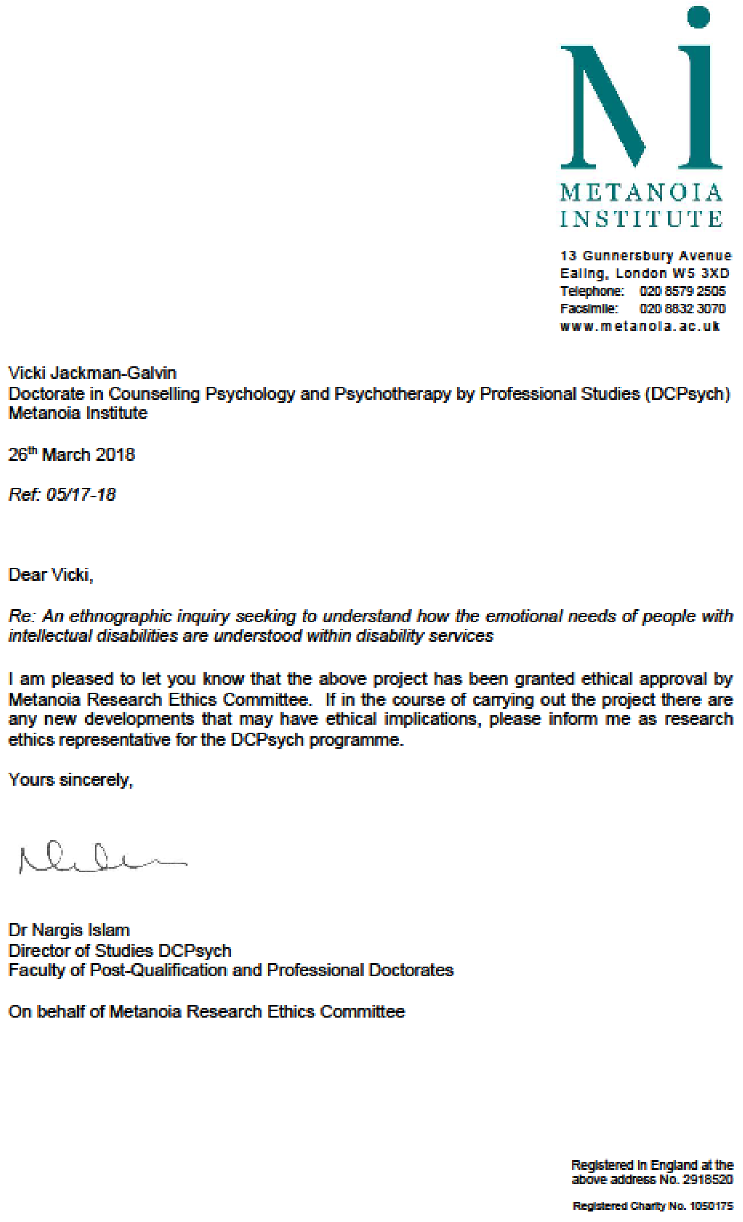
I approve your application and wish you every success with your research.

Yours sincerely,

[redacted]

[redacted]

Appendix D: Ethical approval



METANOIA
INSTITUTE

13 Gunnersbury Avenue
Ealing, London W5 3XD
Telephone: 020 8579 2505
Facsimile: 020 8832 3070
www.metanoia.ac.uk

Vicki Jackman-Galvin
Doctorate in Counselling Psychology and Psychotherapy by Professional Studies (DCPsych)
Metanoia Institute

26th March 2018

Ref: 05/17-18

Dear Vicki,

Re: An ethnographic inquiry seeking to understand how the emotional needs of people with intellectual disabilities are understood within disability services

I am pleased to let you know that the above project has been granted ethical approval by Metanoia Research Ethics Committee. If in the course of carrying out the project there are any new developments that may have ethical implications, please inform me as research ethics representative for the DCPsych programme.

Yours sincerely,

Dr Nargis Islam
Director of Studies DCPsych
Faculty of Post-Qualification and Professional Doctorates

On behalf of Metanoia Research Ethics Committee

Registered in England at the
above address No. 2918520

Registered Charity No. 1050175

Appendix E: Ethical approval (minor amendment)

13 North Common Road
Ealing, London W5 2QB
Telephone: 020 8579 2505
Facsimile: 020 8832 3070
www.metanoia.ac.uk

26/10/2018

Dear Vicki Jackman-Galvin,

I am pleased to let you know that your minor amendments to the project ‘**An ethnographic inquiry seeking to understand how the emotional needs of people with intellectual disabilities are understood within disability services.’** has been granted ethical approval by Metanoia Research Ethics Committee. If in the course of carrying out the project there are any new developments that may have ethical implications, please inform me as Chair of the Research Ethics Committee.

Yours sincerely,

Dr Biljana van Rijn
Chair of Metanoia Research Ethics Committee

Registered in England at the
above address No. 2918520

Registered Charity No. 1050175

Appendix F: Recruitment and information letter (Standard version)

Re. Request for recruitment in a Doctoral Research Study

To whom it may concern,

I am writing to you to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please don't hesitate to contact me (details below) if there is anything that is not clear or if you would like more information.

The study is titled:

Transforming lives: A phenomenological study exploring the experiences of adults with intellectual disabilities and staff of the social processes that impact upon person centred care in residential services in the Republic of Ireland.

The purpose of this study is to explore the experiences of adults with ID and staff of living in residential services. Given the scarcity of research into how social care services meet the needs of adults with ID the aim of this study is to illuminate the individual experiences of adults with ID residing in disability services in Ireland. Hence, the objectives for this study are:

Explore the nature of the relationship between adults with ID and staff.
Identify factors that impact upon the provision of person centred care in residential services.
Explore the nature of organisational culture in disability services and its impact upon the quality of life of adults with ID who live in residential services.

I propose to conduct in depth semi-structured interviews with 6 adults with ID and 6 employees of the disability service. Interviews will last for approximately one hour but this will depend on each participant. If participants wish to stop the interview at any time, the interview will be suspended and a post-interview discussion will take place in order to support the participant. Participants will be reassured that all information will be kept confidential unless any unlawful act of safeguarding issue arises. A second interview with the same participants may be conducted to confirm what has been said previously and explore new issues which may have been mentioned.

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason, up until the point of analyzing the data.

This study may help services to think differently about how people with ID are supported. Any information about the service which is used will have the services name and address removed so that it cannot be recognised from it. All data gathered will be stored, analysed and reported in compliance with GDPR and the Data Protection Act 2018.

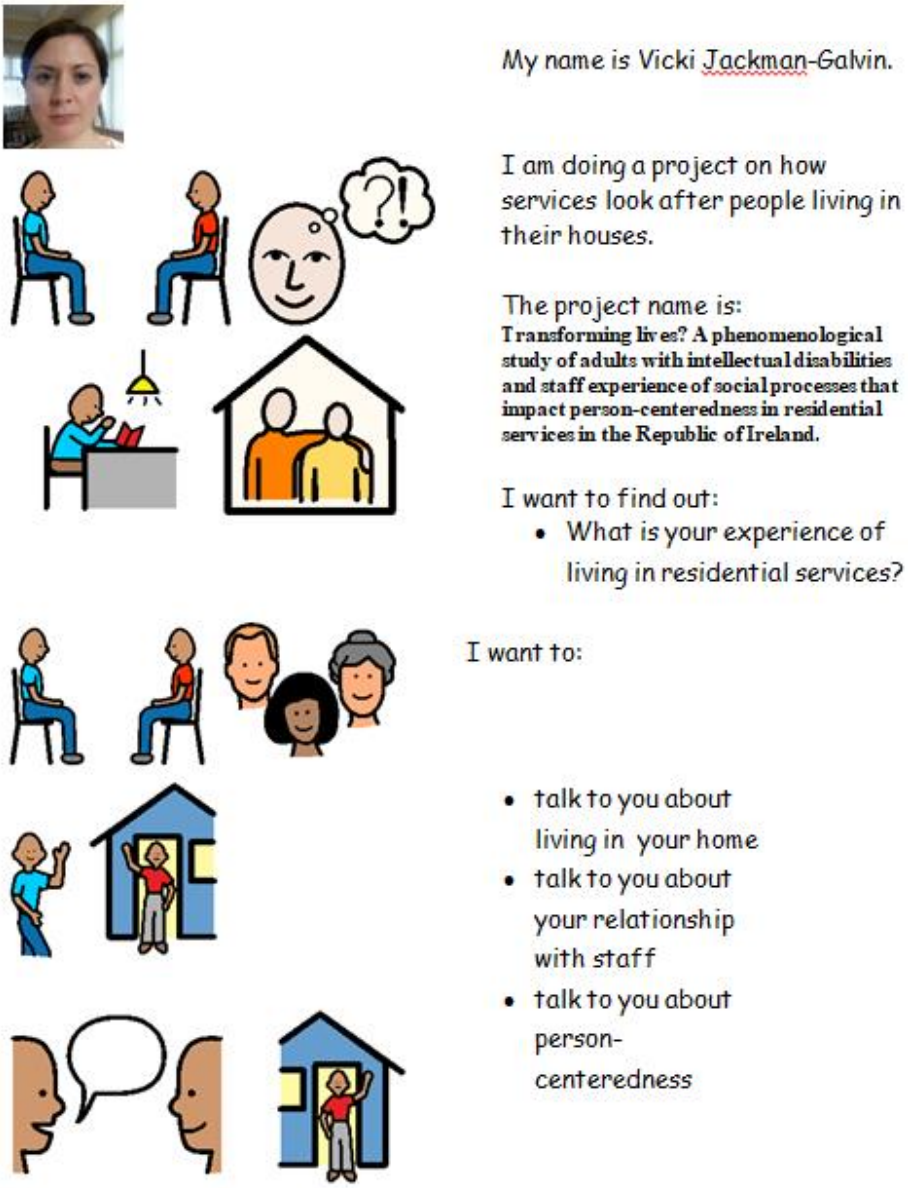
The results of the study will be published as part of my Doctoral thesis. The study has been reviewed and approved by the Metanoia Research Ethics Committee. Please contact me or my Supervisor should you require further information.

Researcher Contact Details:
Vicki Jackman-Galvin
Telephone: 051-359244 Email: vicki.jackman-galvin@metanoia.ac.uk

Supervisor Contact Details:

Dr. Martin Partridge Email: M.Partridge@wlv.ac.uk

Appendix G: Recruitment and information letter (Easy-Read version)



My name is Vicki Jackman-Galvin.

I am doing a project on how services look after people living in their houses.

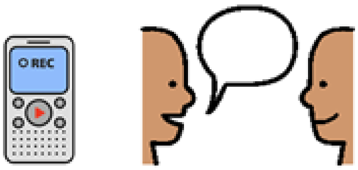
The project name is:
Transforming lives? A phenomenological study of adults with intellectual disabilities and staff experience of social processes that impact person-centeredness in residential services in the Republic of Ireland.

I want to find out:

- What is your experience of living in residential services?

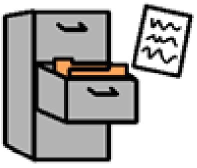
I want to:

- talk to you about living in your home
- talk to you about your relationship with staff
- talk to you about person-centeredness



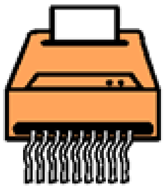
I want to record what you tell me

I will not let anyone see my notes or hear the recording.

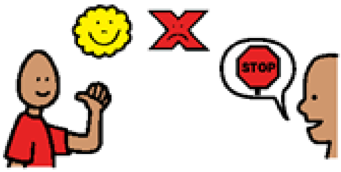


I will lock away my notes.

Your name will not be written on my notes.



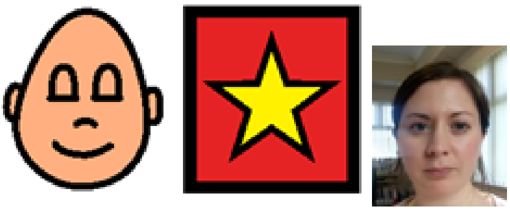
When the project is finished I will shred my notes.



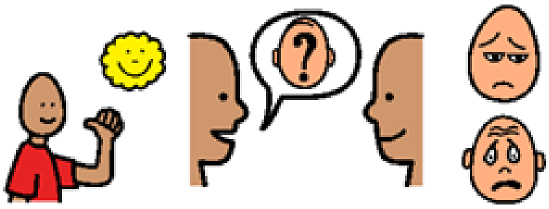
It is your choice if you want to take part in the project.

You can say yes or no.

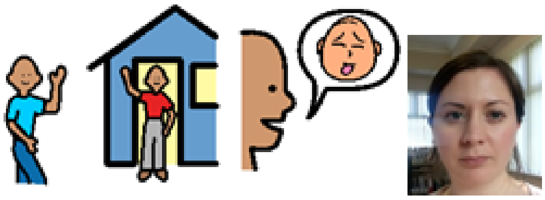
You can stop at any time up until I analyse the data.



Your safety is very important to me.

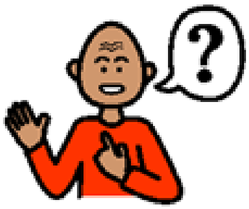


If taking part in the project makes you feel upset you can talk to your keyworker, another staff member or someone else.



If when we talk, you tell me bad things that have happened or are happening to you which means you are not safe. I will have to tell the person in your service who takes care of people's safety (name).

If this happens I will talk to you more about it.

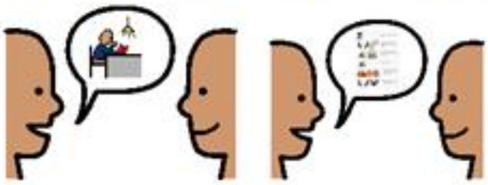


If you have any questions about this project:

you can telephone me at 051-xxxxx

you can send me an e-mail at vicki.jackman-galvin@metanoia.ac.uk

I will telephone you in a few days to see if you would like to meet me or not.



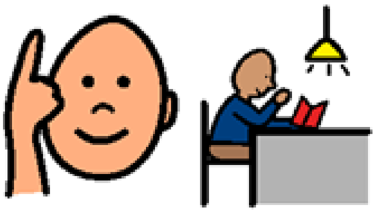
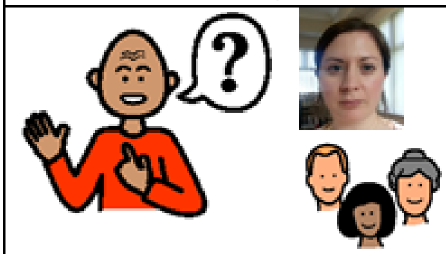
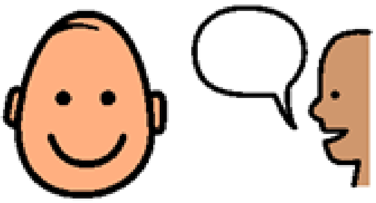
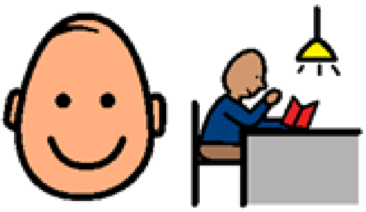
If you want to meet me I will talk to you about this information sheet.

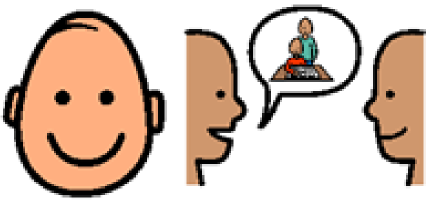
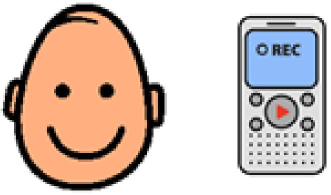
Appendix H: Consent form (Easy-Read version)

Project Consent Form

Tick box ✓

Transforming lives: A phenomenological study exploring the experiences of adults with intellectual disabilities and staff of the social processes that impact upon person centred care in residential services in the Republic of Ireland.

		☺ Yes	✗ No
	Do you understand what this study is about?		
	Have you had a chance to ask questions and talk to me or staff about this study?		
	Are you happy with the answers given to the questions you have asked me or staff about the study?		
	Are you happy to take part in this study?		

		Yes	No
	Are you happy for me to talk to you about what it's like to live in residential services?		
	Are you happy for me to record what you tell me?		

Participants name:____

Participants Signature:____

Date: ____

Witness/Next of Kin:____

Appendix I: Consent form (Standard version)

CONSENT FORM

Participant Identification Number:

Title of Project: Transforming lives? A phenomenological study of adults with intellectual disabilities and staff experience of life in community residential services in the Republic of Ireland.

Name of Researcher: Vicki Jackman-Galvin

Please initial bo

1. I confirm that I have read and understand the information sheet dated ....……………………for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time up until the point of analysing the data, without giving any reason. If I choose to withdraw, I can decide what happens to any data I have provided. ☐
3. I understand that my interview will be audio-recorded and subsequently transcribed ☐
4. I agree to take part in the above study. ☐
5. I agree that this form that bears my name and signature may be seen by a designated auditor. ☐

Name of participant	Date	Signature
Researcher	Date	Signature

Appendix J: Interview schedule

Interview Introduction:

Thank you for taking the time to speak to me today.

This interview will last approximately an hour, although it can be longer or shorter if you wish. The interview will be recorded on a Dictaphone, is that OK?

You can stop the interview whenever you wish and you are welcome to take a break if you need to.

Your name and identifiable information will be changed so that you are not identifiable. The only time I would need to break confidentiality is if you inform me that you or someone else is at risk of harm. Do you understand?

The purpose of this interview is to develop a really good understanding of your day to day work supporting people who live within the service/what it is like to live within disability services. There are no right or wrong answers – I am interested in hearing about your experiences in the way that you want to tell me about them.

Semi Structured Interview Schedule – Mangers/Multi-D/Frontline Staff

Opening Question and additional prompts

Question 1: I would like to get to know you a little, can you tell me about what brought to working in social care?

What is your role as (Social Care Leader, Care Assistant…) involve?

What does a normal day/week look like?

Question 2: At the moment what do you understand the aim of the service is?

Can you tell me about any difficulties in fulfilling this aim within your role?

What are the difficulties…

Question 3: What is your experience of supporting adults with ID who live in residential services?

Question 4: What do you understand is your role?

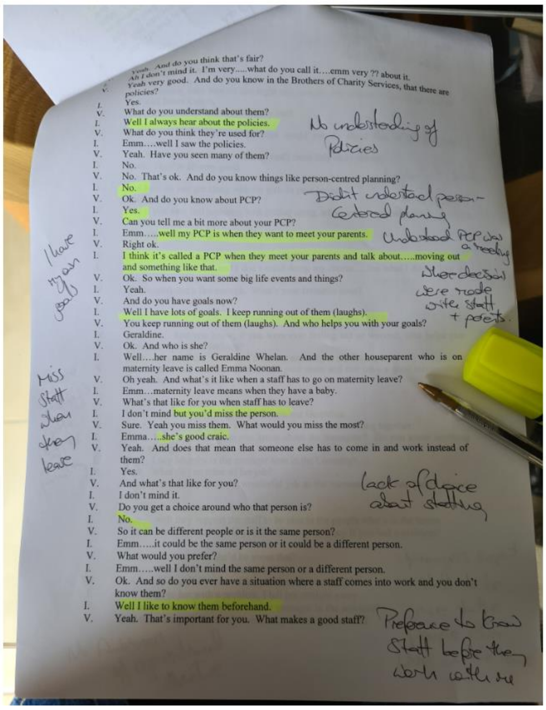
Question 5: What is your experience of person-centred care?

Semi-Structured Interview Schedule – Adults with ID

Opening Question and additional prompts

Question 1:	I would like to get to know you a little, can you tell me about your childhood and when you came to live in the services?
	What was is like when you had to leave home?
	What is a normal day look like?
Question 2:	At the moment what do you understand is the aim of service for you?
Question 3:	Can you tell me what person centred means for you?
	Can you tell me about any difficulties you’ve experiences that were not person centred?
Question 4:	Can you tell me about your relationship with staff?
Question 5:	How do you access support if you’re not feeling happy?

Appendix K: Generating initial codes



Yeah. And do you think that's fair?
Ah I don't mind it. I'm very.....what do you call it....emm very ?? about it.
V. Yeah very good. And do you know in the Brothers of Charity Services, that there are policies?
I. Yes.
V. What do you understand about them?
I. Well I always hear about the policies.
V. What do you think they're used for?
I. Emm....well I saw the policies.
V. Yeah. Have you seen many of them?
I. No.
V. No. That's ok. And do you know things like person-centred planning?
I. No.
V. Ok. And do you know about PCP?
I. Yes.
V. Can you tell me a bit more about your PCP?
I. Emm.....well my PCP is when they want to meet your parents.
V. Right ok.
I. I think it's called a PCP when they meet your parents and talk about.....moving out and something like that.
V. Ok. So when you want some big life events and things?
I. Yeah.
V. And do you have goals now?
I. Well I have lots of goals. I keep running out of them (laughs).
V. You keep running out of them (laughs). And who helps you with your goals?
I. Geraldine.
V. Ok. And who is she?
I. Well....her name is Geraldine Whelan. And the other houseparent who is on maternity leave is called Emma Noonan.
V. Oh yeah. And what's it like when a staff has to go on maternity leave?
I. Emm...maternity leave means when they have a baby.
V. What's that like for you when staff has to leave?
I. I don't mind but you'd miss the person.
V. Sure. Yeah you miss them. What would you miss the most?
I. Emma.....she's good craic.
V. Yeah. And does that mean that someone else has to come in and work instead of them?
I. Yes.
V. And what's that like for you?
I. I don't mind it.
V. Do you get a choice around who that person is?
I. No.
V. So it can be different people or is it the same person?
I. Emm.....it could be the same person or it could be a different person.
V. What would you prefer?
I. Emm.....well I don't mind the same person or a different person.
V. Ok. And so do you ever have a situation where a staff comes into work and you don't know them?
I. Well I like to know them beforehand.
V. Yeah. That's important for you. What makes a good staff?

No understanding of Policies

Didn't understand person-centred planning

Understood PCP was a meeting

Where decision were made with staff + parents.

I have my own goals

Miss staff when they leave

lack of choice about staffing

Preference to know staff before they work with me

Step 1 Analysis – Initial codes & Themes

Theme: Individual experience of coming into residential care	**Theme: People with ID living in residential care have limited choice**	**Theme: People with ID living in residential care feel a burden on staff**
Codes:	**Codes:**	**Codes:**
Not my choice Parent died Sibling decided Parents thought it would be a good idea I was ready to move out Era of institutionalisation	I didn't get to choose where and with whom I live It took many years for me to get to live independently I've had to move to many different houses I don't like living with people who shout My parents and staff met to make decisions Managers can make things happen	I don't want to bother staff Staff are too busy Can't get enough staff Staff don't have time to support me access my preferred activities I don't want to rock the boat

Theme: Level of support needed in residential care **Codes:** Not enough staff Always short staffed High support needs (staff make my meals, give me my medication and take care of me) versus living independently (Staff support me for a couple of hours on Tuesday's and Fridays) Services are slow to meet the needs of people who live in residential care	**Theme: Quality of care/support of people with ID living in residential care** **Codes:** Staff do their best and are good fun It's more than just a job, it's my life Staff have a responsible job Not all staff are able for the job Staff training and reality of the work are very different Staff should spend more time getting to know me More staff are needed to facilitate my choices	**Theme: Limited opportunity within residential services for people with ID to maximise their independence** **Codes:** It took me a long time to gain my independence, people thought I wouldn't be able Services are slow to meet people's needs Our house is far out in the country and we rely on staff to drive us everywhere Staff cook all my meals, they worry I would eat too much My previous day service wasn't wheelchair accessible My bedroom is a converted garage and is wheelchair accessible but the rest of the house is not
Theme: People with ID's understanding of person centeredness **Codes:**	**Theme: The relationship people with ID living in residential care have with paid staff workers**	**Theme: Past trauma in the lives of people with ID living in residential care** **Codes:**

I don’t know what person centred is sorry (ALL) Yes I know what PCP is -It’s a meeting -My PCP is only as good as the staff support I receive -My mother and staff meet first and then I join the meeting later -My PCP meeting is all about me -I get to talk about going to places My keyworker gets things done I don’t know about the PCP policy (ALL)	**Codes:** Staff are fun Staff make me feel safe I can talk to staff It’s hard for me to develop trust with others Staff don’t have time to get to know me It’s really hard when staff leave It’s hard to find ‘good’ staff ‘Good staff’ are not easy come by Staff have a hard job Not all staff are able for the job There needs to be a good fit between me and staff I don’t choose which staff work with me	Community living doesn’t change the past It’s been a hard life No one asks you how do you feel It’s hard for me to trust others It’s all crisis management Staff have wrong perceptions about behaviours
Theme: Sociocultural/Organisational culture **Codes:** Organisational policies are not accessible to people with ID living in residential care Belief that it’s hard to get staff to work in ID residential services There is not enough money/Government are too blame Change is slow Not enough staff training	**Theme: Emotional Well-being of people with ID living in residential care** **Codes:** It wasn’t easy to move out of my home I’m unhappy living with people who shout Staff leave It’s hard to get good staff I worry when staff are sick No one asks you how you feel	

	It’s been a hard life	

Theme: Different reasons for choosing to work in disability	**Theme: Interpretation of role/Different roles working within a disability service**	**Theme: Ideologies that guide practise/Aim of the service**
Codes: Personal reasons/family member with a disability Wanting to make a difference/be the change/advocate	**Codes:** Supporting person centred planning Linking in with family’s, day services Building community links Helping people find their voice Listen to what they want Get a good service Meeting people’s needs Making sure staff deliver a quality service Making sure staff are trained Health and Safety Safety of buildings Policy making Live a life of their choosing Giving people with ID their rights Managing budgets Liaising with outside agencies	**Codes:** Social Role valorisation Person centred Organisational Ethos is to be person cantered

	HIQA compliance Reflecting the ethos of the organisation Ensuring we have adequate resources The link communicating between senior management and front-line teams	
Theme: Issues that prevent implementing service aims **Codes:** There isn't individualised funding The idea of people with ID living independently is new (social issue) Never looking forward/fire-fighting (organisational) Time of transition/revolution of disability services / history Lack of resources Inadequate physical buildings Change is slow** Staff attitude Culture Older institutionalised history vs younger services expectations are higher (older SU's de-sensitized) Increased paper-work HIQA not person-centred Hard to define person centeredness and what it means Hard to move things on	**Theme: Positive changes** **Codes:** HIQA – accountability Individualised funding Independent living - choice	**Theme: Societal attitude/Organisational culture** **Codes:** Slow to catch on ? Presence of ID what does it project Don't use systems as intended (TBPM) We are always looking at what's going wrong and what needs to be done next – we never look at what we've actually achieved Aspirational view/Hope History around people with intellectual disability….seeing the intellectual disability rather than the person, I think

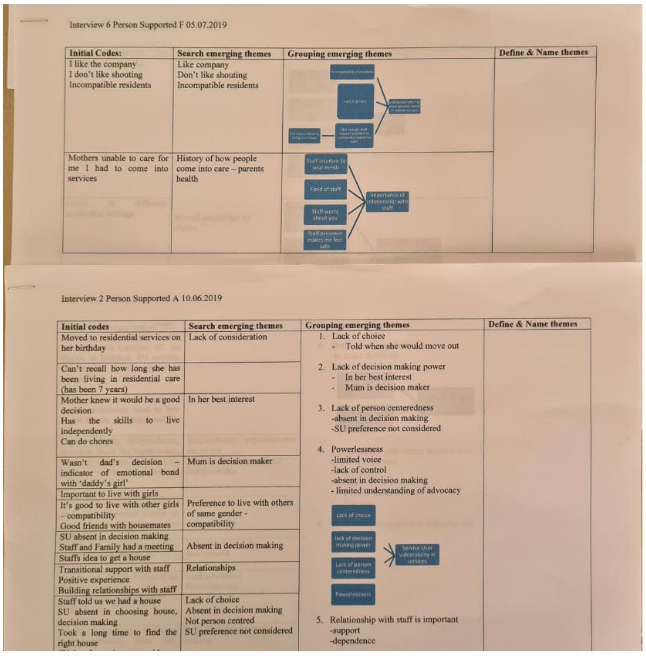
		so….thinking about it and just the way things have been structured for years, it's a duty of care….we're only in the process of moving to the new models of working with people. Societies attitude (pity)is a barrier to Community integration
Theme: Person-centred **Codes:** Hard to define Not sure we do it right Don't think we give residents enough credit for what they do understand	**Theme: Frustrations/Challenges** **Codes:** Working from own initiative (I had to) We are always fire-fighting We are never looking forward Un-prepared If residents and families push for it change happens quicker for them Don't use systems as intended (TBPM) Too much paperwork Stuck in the middle of change Policies are not being implemented Staff are stretched	**Theme: The process of change** **Codes:** Is very slow Staff attitude Culture Expectations are different between institutionalised and young HIQA needs to be more person-centred You need to feel part of a team with a shared goal of improving the service for people who are using it

	Limited control – budgets Dilemma managing budgets and providing person centred support	
Theme: Emotional needs/Well-being **Codes:** Family can meet some needs but not all (adult needs) If you don’t have any family support We can support the nuts and bolts of daily living but the biggest need we can’t satisfy is loneliness Institutional histories/hierarchies amongst peers Abuse Histories people can’t even tell us about More support for people who have been abused	**Theme: Need for space/time/reflection** **Codes:** I think by sitting and reflecting in a nice way, and using that day, it gives people a sense of purpose; it gives them a sense of achievement; and it gives them a sense of motivation to go “oh ok let’s go ahead”.	**Theme: Staff attitude/hierarchy/disconnect between top down** **Codes:** If managers at the top don’t model the values of the organisation then how will front-line staff…it’s all about budgets and money not real people Important to model behaviour that values people doing things for people as opposed to side-by-side support. Staff attitude gets in the way of implementing policies communication; 2) staff attitude; and I’m going to say 3) bad management. There is no training department that’s going to teach anybody’s attitude and values relying on an intrinsic good natured support worker
Theme:	**Theme: Relationship**	**Theme: Benefit of policies**

Codes: Need a good staff team Health & Safety (service) demands butt heads with normal living Managers are often out on the floor not getting time to their job Too many short-term contracts no-one is there for the long-run Lose sight of the person when running around ensuring the budget is compliant and everything is in its right place in the house (impact on people with ID) Younger staff don't have a sense of the powerlessness of the older generations of PWID	**with People using services** **Codes:** Need to instil confidence Trying to get the balance between providing a service and trying to support people to live a normal life Don't think we acknowledge the relationships between staff and SU Minding and protecting people versus supporting people to live the life they choose (medical model vs. Social model)	**Codes:** Policies can improve services and change staff attitude if they are reviewed with teams often Safeguarding is paramount but the policy of valuing people that's the one that I push with new staff Many of the policies are covering ourselves to protect from past incidents It's hard to get through our well-meaning with people who have significant disabilities (communicating with PWID) It can sometimes appear tokenistic (support) Policies are not individualised to different Service areas (individualised supports) Staff guilt half the time people are printing it and putting it in a

		file…(policies) Policies are not really understood

Appendix L: Searching for themes



Interview 6 Person Supported F 05.07.2019

Initial Codes:	Search emerging themes	Grouping emerging themes	Define & Name themes
I like the company I don't like shouting Incompatible residents	Like company Don't like shouting Incompatible residents		
Mothers unable to care for me I had to come into services	History of how people come into care – parents health		

Interview 2 Person Supported A 10.06.2019

Initial codes	Search emerging themes	Grouping emerging themes	Define & Name themes
Moved to residential services on her birthday	Lack of consideration	1. Lack of choice - Told when she would move out 2. Lack of decision making power - In her best interest - Mum is decision maker 3. Lack of person centeredness -absent in decision making -SU preference not considered 4. Powerlessness -limited voice -lack of control -absent in decision making - limited understanding of advocacy 5. Relationship with staff is important -support -dependence	
Can't recall how long she has been living in residential care (has been 7 years)			
Mother knew it would be a good decision Has the skills to live independently Can do chores	In her best interest		
Wasn't dad's decision – indicator of emotional bond with 'daddy's girl'	Mum is decision maker		
Important to live with girls It's good to live with other girls – compatibility Good friends with housemates	Preference to live with others of same gender - compatibility		
SU absent in decision making Staff and Family had a meeting Staffs idea to get a house	Absent in decision making		
Transitional support with staff Positive experience Building relationships with staff	Relationships		
Staff told us we had a house SU absent in choosing house, decision making Took a long time to find the right house	Lack of choice Absent in decision making Not person centred SU preference not considered		

Preliminary Themes Service Users

Theme: Individual experience of coming into residential care	Theme: People with ID living in residential care have limited choice	Theme: People with ID living in residential care feel a burden on staff
Codes: Not my choice Parent died Sibling decided Parents thought it would be a good idea I was ready to move out Era of institutionalisation	**Codes:** I didn't get to choose where and with whom I live It took many years for me to get to live independently I've had to move to many different houses I don't like living with people who shout My parents and staff met to make decisions Managers can make things happen	**Codes:** I don't want to bother staff Staff are too busy Can't get enough staff Staff don't have time to support me access my preferred activities I don't want to rock the boat
Theme: Level of support needed in residential care **Codes:** Not enough staff Always short staffed High support needs (staff make my meals,	**Theme: Quality of care/support of people with ID living in residential care** **Codes:** Staff do their best and are good fun It's more than just a job, it's my	**Theme: Limited opportunity within residential services for people with ID to maximise their independence** **Codes:** It took me a long time to gain my

give me my medication and take care of me) versus living independently (Staff support me for a couple of hours on Tuesday's and Fridays) Services are slow to meet the needs of people who live in residential care	life Staff have a responsible job Not all staff are able for the job Staff training and reality of the work are very different Staff should spend more time getting to know me More staff are needed to facilitate my choices	independence, people thought I wouldn't be able Services are slow to meet people's needs Our house is far out in the country and we rely on staff to drive us everywhere Staff cook all my meals, they worry I would eat too much My previous day service wasn't wheelchair accessible My bedroom is a converted garage and is wheelchair accessible but the rest of the house is not
Theme: People with ID's understanding of person centeredness **Codes:** I don't know what person centred is sorry (ALL) Yes I know what PCP is -It's a meeting -My PCP is only as good as the staff support I receive -My mother and staff meet first and then I join the meeting later -My PCP meeting is all about me -I get to talk about going to places My keyworker gets things done I don't know about the PCP policy (ALL)	**Theme: The relationship people with ID living in residential care have with paid staff workers** **Codes:** Staff are fun Staff make me feel safe I can talk to staff It's hard for me to develop trust with others Staff don't have time to get to know me It's really hard when staff leave It's hard to find 'good' staff 'Good staff' are not easy come by Staff have a hard job Not all staff are able for the job There needs to be a good fit between me and staff I don't choose which staff work with me	**Theme: Past trauma in the lives of people with ID living in residential care** **Codes:** Community living doesn't change the past It's been a hard life No one asks you how do you feel It's hard for me to trust others It's all crisis management Staff have wrong perceptions about behaviours
Theme: Sociocultural/Organisational culture **Codes:** Organisational policies are not accessible	**Theme: Emotional Well-being of people with ID living in residential care** **Codes:**	

to people with ID living in residential care Belief that it's hard to get staff to work in ID residential services There is not enough money/Government are too blame Change is slow Not enough staff training	It wasn't easy to move out of my home I'm unhappy living with people who shout Staff leave It's hard to get good staff I worry when staff are sick No one asks you how you feel It's been a hard life	

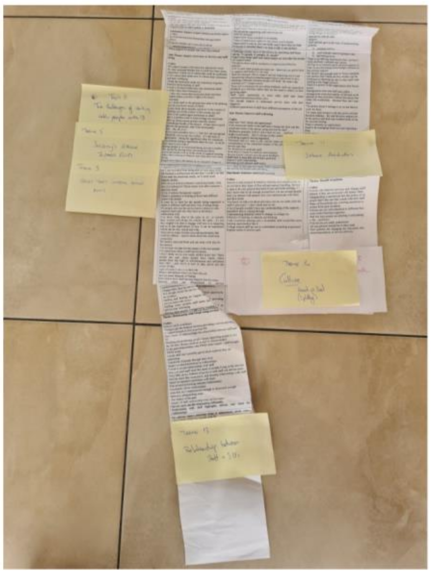
Preliminary Themes Staff

Theme: Different staff roles working within a disability service	**Theme: Issues that prevent implementing service aims**	**Theme: Societal attitude/Organisational culture**
Codes: Supporting person centred planning Linking in with family's, day services Building community links Helping people find their voice Listen to what they want Meeting people's needs Making sure staff deliver a quality service Making sure staff are trained Health and Safety Safety of buildings Policy making Live a life of their choosing Giving people with ID their rights Managing budgets Liaising with outside agencies HIQA compliance Reflecting the ethos of the organisation Ensuring we have adequate resources	**Codes:** There isn't individualised funding The idea of people with ID living independently is new (social issue) Never looking forward/fire-fighting (organisational) Time of transition/revolution of disability services / history Lack of resources Inadequate physical buildings Change is slow Staff attitude Culture Older institutionalised history vs younger services expectations are higher (older SU's de-sensitized) Increased paper-work HIQA not person-centred Hard to define person centeredness and what it means Hard to move things on	**Codes:** Slow to catch on Don't use systems as intended (TBPM) We are always looking at what's going wrong and what needs to be done next – we never look at what we've actually achieved History around people with intellectual disability….seeing the intellectual disability rather than the person Societies attitude (pity)is a barrier to Community integration Break society views in the service by reminding staff keep saying 'it's people, it's people, its' people" fearful that the organisation is going towards focusing on budget as opposed to people, and when you go to senior management meetings that I find a challenge…that while we're pontificating person-centeredness, on the other hand we're saying "budget budget budget".

Theme: Emotional needs/Well-being of service users **Codes:** Family can meet some needs but not all (adult needs) If you don’t have any family support We can support the nuts and bolts of daily living but the biggest need we can’t satisfy is loneliness Institutional histories/hierarchies amongst peers Abuse Histories people can’t even tell us about More support for people who have been abused It used to be about behaviour only emotional needs wouldn’t have been focussed on It’s only very recent that emotional abuse has been included where you have a right to be secure emotionally We only think about peoples emotions in the context of psychiatry not in the context of the normal ups and downs of life (pathologies pwid/seen as other) There’s a definite need to acknowledge the emotional needs e.g. bereavement groups (specific issues) the emotional health of the person…if they have a good balanced life generally, they’ll be emotionally better…like all of us. I don’t think staff on the ground have time to be thinking about the	**Theme: Need for space/time/reflection** **Codes:** I think by sitting and reflecting in a nice way, and using that day, it gives people a sense of purpose; it gives them a sense of achievement; and it gives them a sense of motivation to go “oh ok let’s go ahead”. Supervision keeps staff well which means we look after the people we support better You will come up with resistance The organisation is built on the staff Supervision when available is invaluable Value of supervision, space to vent, know you’re heard Our system is too hierarchical Supervision is seen as nice and fluffy (don’t have time for that) Everyone is stretched there’s no time to talk to one another	**Theme: Staff Relationship with People using services** **Codes:** Need to instil confidence Trying to get the balance between providing a service and trying to support people to live a normal life Don’t think we acknowledge the relationships between staff and SU Minding and protecting people versus supporting people to live the life they choose you probably have 1:1 time but you don’t have any…you’re not special to anybody you’re just one of four…it’s that lack of significance…being the significant other for somebody or somebody being a significant other for you…it can be very hard to live with it

emotional needs of PWID Seeing people as an emotional being not just a number We should be having more conversations about emotional needs such as at the circle of support meeting rather than looking at finances and what they have been doing People have had a life before us we shouldn’t forget it and understand it comes out in different ways		

Appendix M: Reviewing themes



Theme A: Organisational culture	
Sub-theme A1	Sub-theme A2
Culture of disempowerment	Lack of collaboration and poor communication
Codes: Mis/communication in the service Accessibility of buildings Lack of understanding Lack of choice Absent in decision making ? what is service user role in service SU de-sensitized to lack of choice/control over their life Limited voice Lack of control/power Victim Limited awareness of service structures and supports If managers at the top don't	Codes: No-one asks you how do you feel "It's all crisis management" Staff give a lot without getting much back Staff are not invited to develop such templates Staff need to be recognised as professionals in their own right We are always fire-fighting We are never looking forward Staff feel un-prepared Don't use systems as intended (TBPM) Too much paperwork Stuck in the middle of change Staff roles need to made clearer It's unclear at times what's expected of staff and they have a lot of competing

model the values of the organisation then how will front-line staff…it’s all about budgets and money not real people Important to model behaviour that values people doing things for people as opposed to side-by-side support. Staff attitude gets in the way of implementing policies communication; staff attitude; and I’m going to say bad management. There is no training department that’s going to teach anybody’s attitude and values relying on an intrinsic good natured support worker Fear we are becoming more budget oriented and less person centred We haven’t got enough time to focus completely on one person, and I think the key worker can be swamped in planning the day-to-day stuff without looking at the bigger picture. There is a power in the organisation that focuses on money Management aims and staff aims differ – management want	demands – how do they balance priorities Misunderstood person centred Different perceptions of PCP Limited understanding of PCP Accessibility of policies Accessibility of terms used (Person centred vs. PCP)

best quality of life and on the ground its best activities without the pieces that make life worthwhile - because they can't reach on them The person doesn't belong to us we are here to work for them Too many gate-keepers with the power around decision-making – the real decision makers should be the person and their key-worker/circle of support Managers have the power to make things happen Stuck	

Theme B: Importance of relationships	
Sub-theme B1	Sub-Theme B2
Reciprocity of relationships between staff and service users	The importance of relationships in the lives of people with ID
Codes: Need to instil confidence Trying to get the balance between providing a service and trying to support people to live a normal life Don't think we acknowledge the relationships between staff and SU Minding and protecting people versus supporting people to live the life they choose (medical model vs. Social	Dependant on staff to meet needs (? All needs) Successful PCP is dependent on staff support Staff make decisions Staff decide Staff look after me I don't want to bother staff Enjoy company of staff Staff don't have the time Seeking more staff support Practical support vs. Emotional/Relational support

model) In the past relationships with PWID were fudged – staff brought PWID home Locum staff can’t possibly get to know a person they are supporting Treadmills of people through their lives Impact on attachment/trust in relationships Forced to accept relationships with staff How can paid staff meet the needs of people living in the services Very little choice balance of power is with staff not service users Service users like consistency and develop relationships with staff based on repeated experience with them Fear around promoting intimate relationships Uncertainty about relationships Area that isn’t implemented enough or discussed enough Seen as a safeguarding issue The impact of the past Impact of staff relationship with service users Service users see the relationship differently	Not enough staff Staff help me/look after me I prefer the company of staff Staff are not family Only staff can talk to me Staff do their best Emotional connection with staff Good vs. Bad Staff Staff should get to really know me Hard to get ‘good’ staff Staff don’t have time to get to know me I have to have strangers support me in my home Can’t survive without staff support Developing relationships takes time Staff have a big responsibility Not all staff have the right attitude Staff can have negative perceptions on SU’s Attitudes of staff Staff need to better informed of the realities of the job (“It’s not just a job, it’s my life” “Staff need to understand it’s people’s lives” “If people with ID didn’t exist, staff wouldn’t have jobs” Right fit off staff Would like a choice of staff “Service users need more support, not just brought to places”

Relationship with staff highlights service user need for relationships The service hasn’t resolved what it understands about what relationships means for people with ID Narrative that all people with ID are vulnerable and need protecting	
Theme C: Need for support	
Sub-theme C1	Sub-theme C2
Impact of living in residential care	Creating space to reflect on socio-emotional needs of service users and staff
Impact of past trauma Impact of (enforced) change Impact of living in residential care Impact of staff (relationship) on service users not enough staff to provide support Staff are too busy I can’t go out without staff Loss when staff leave (loss of relationship, loss of knowledge, loss of identity)	I think by sitting and reflecting in a nice way, and using that day, it gives people a sense of purpose; it gives them a sense of achievement; and it gives them a sense of motivation to go “oh ok let’s go ahead”. Supervision/reflective practice is not the norm in the service We should be supporting staff and we are not Staff are stressed Supervision when available is invaluable Value of supervision, space to vent, know you’re heard Supervision is seen as nice and fluffy (don’t have time for that)

	Everyone is stretched there’s no time to talk to one another Challenge society views in the service by reminding staff keep saying ‘it’s people, it’s people, its’ people” Supervision keeps staff well which means we look after the people we support better Perception there will be resistance to supervision/reflective practise EAP is used when people are burnt out – there isn’t an active layer to support staff before it’s too late Staff are stressed with no support and are beginning not to care Introducing reflective practise/supervision is perceived to be a challenge culturally because people will think “ah what’s she wanting now?”,(supervision) There isn’t a structure for providing feedback, staff can experience feedback as a criticism rather than see the need to reflect on their growing edges Staff value opportunity to meet other staff and share opinions/brainstorm/problem solve Not enough support to understand

	service users with dual diagnosis Different generations of staff have different perceptions of the job

Appendix N: Defining and naming themes

<table>
<tr><td colspan="3">Theme A: Reality of living in residential care Impact of living in residential care on service users emotional well-being
First theme represents both service user and staff's perceptions of how the realities of living in residential care impact service users emotional well-being. This main theme of service user emotional well-being is made up of 3/4 sub-themes.</td></tr>
<tr><td>Sub-theme A1</td><td>Sub-theme A2</td><td>Sub-theme A3</td></tr>
<tr><td>The meaning of relationships in disability services</td><td>Subjective experience of living in residential care</td><td>Contextual impact</td></tr>
<tr><td colspan="3">Theme B: Challenges to delivering person cantered care for people with ID living in residential care
This second theme represents both service user and staff's sense of the gap between person-cantered policy and approaches and actual care on the ground. This main theme of person-cantered care is made up of 3/4 sub-themes.</td></tr>
<tr><td>Sub-theme B1</td><td>Sub-Theme B2</td><td>Sub-theme B3</td></tr>
<tr><td>Person cantered care is hard to define</td><td>There is no choice - systemic issues to delivering person cantered care</td><td>Permission for people with ID to be the expert in their own care</td></tr>
<tr><td colspan="3">Theme C: Shared Needs
This third theme represents the needs for more support and training for staff and service users</td></tr>
<tr><td>Sub-theme C1</td><td>Sub-theme C2</td><td>Sub-theme C3</td></tr>
<tr><td>Support to cope with and understand emotional difficulties</td><td>Dehumanisation in disability services /Unhelpful dialogues/shared communication/silence/no space to think about the emotional well-being of service users/emotional impact on staff</td><td>Need for more support and training</td></tr>
</table>

List of sub-themes, frequencies and sample quotes for over-arching theme 1

No	*Sub-Theme*	*No of Cases*	*Sample Quote*
1	Relationship between service users and staff	12	*"And it was said to me 'it's only a job like'….and I said 'it might be to you but it's not to me'….I was working probably 10 years with that person, and I just felt he was like a second part of my family" – Katy, Staff*
2	Power & Control	11	*"But we're forced to be in their life because we're a paid service in their life, and they're forced to have to accept us" – Karen, Staff*
3	Process of change is slow	9	*"You can see what needs to happen to support people in a way that you would like them to be supported, but it's so slow for change to be effective for them" – Karen, Staff*
4	Disabling attitudes	6	*"Well I don't like people being judged…sometimes people do be judged….which is not nice. I know people judged me.. They thought I wouldn't be better than any of the rest of them….that I wouldn't have got where I am today…."(Robert, Service user)*

List of sub-themes, frequencies and sample quotes for over-arching theme 2

No	*Sub-theme*	*No of Cases*	*Sample Quote*
1	No shared understanding of person centred care	*12*	*"it really does depend on who you're dealing with…. everyone's definition of person-centeredness is slightly different" (Claire - Staff)*
2	There is no choice	*9*	*"I choose where I live" is normally one that I always….not like laugh at but I kind of go…..ya know this is not happening like….and I don't know how it will happen" (Brian - Staff)*
3	Funding crisis	*12*	*"there was a time we'd bake all evening with the lads and now with HIQA coming on board, I just feel everything is paper, paper, paper, paper" (Katy – Staff)*

List of sub-themes, frequencies and sample quotes for over-arching theme 3

No	*Sub-theme*	*No of cases*	*Sample Quote*
1	Emotional Support	*9*	*"But if the emotional needs of staff aren't met how can we meet the emotional needs of service users"(Maura – Staff)*
2	Time	*10*	*"No-one brings me...staff have no time to bring me to the cinema" (Laura – Service user)*
3	Training and Supervision	*7*	"*we're always looking at*

	what’s going wrong, and what needs to be done next – and we’re never looking at what we’ve actually achieved. And I think by sitting and reflecting in a nice way, and using that day, it gives people a sense of purpose; it gives them a sense of achievement; and it gives them a sense of motivation to go “oh ok let’s go ahead” (Maura – Staff)

Appendix O: Reflexive journal extracts

19.07.2018: I spoke with services manager to seek contact details of another residential service in the hope of recruiting participants. I explained to her that after an initial information session, which I had thought was positive and had generated interest I was surprised that staff had contacted me by email to decline participation on behalf of the service users. I was surprised by the service manager's suspicion that she thought staff were anxious about my potential observation process and she thought this may have influenced resident's decision to refuse. I am wondering why staff did not voice their concerns if this is the case. It is for residents to decide to participate or not? Are staff speaking on behalf of themselves or service users? This suggests an interesting power dynamic between staff and service users?

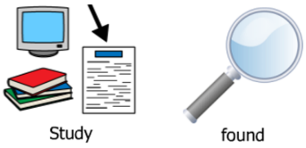
06.09.2018: I met with all four service users this evening; a regular staff member was on duty. I observed staff to be anxious regarding my research. I asked the staff member did they wish to talk to me about it. Staff expressed concern that my presence would agitate one of the residents and it might not be a good idea to conduct my research here. I met residents in the sitting room. One service user expressed his annoyance and asked how long I would be as he was watching Eastenders. Another service user was reluctant to meet but did so after some reassurance from staff. Two service users were very eager to discuss the research and expressed their interest. The service user who expressed annoyance left the room and slammed the door shut. After reassuring everyone that it was their choice to participate or not I left. I noticed my own feelings of annoyance when I left. I had asked staff when arranging the information session what time would suit everyone for me to call. It seemed that when residents were informed there was not much consideration given about how my visit would disrupt their evening plans and I empathised with the service user that I called at a wrong time and disrupted his viewing TV. I felt bad that I had ruined his evening.

23.02.2019: Reflections after interview with service user: There's an emptiness in the lives of some adults with ID and a need for more meaningful relationships. I am struck by the depth of loneliness and how they must wait for staff to organise their social connections. Outside of family and staff many do not experience real friendships. Service users look for a lot from staff – seeking staff to meet all of their needs. Staff mean more in the lives of service users than get credit for or even realise themselves?? The boundaries between staff and service users are tricky – who decides on the boundary? Social care is more than just a job I think I would find it very difficult to manage and hold the complexities of the job (intimate care, challenging behaviour, health issues, meeting social and emotional needs, managing accounts, cooking, cleaning….). I am struck by how the role mirrors that of a parent in a home?? The parentifying of the job is this my perception or a projection??

Service users seem to have a lack of choice around who they live with. Some are talking about the incompatibility of fellow residents. Staff can come and go and leave when they want to but a sense that service users are trapped/stuck?

23.09.2020: Working through staff data – Why am I feeling anger, frustration, anxiety?? Are these projected feelings? Is this what occurs in the face of ID. I feel a strong need for more support, help to understand, help to see beyond the chaos? Help to see beyond disability!!! I am feeling intense feelings of impossibility and of being stuck? A word that continues to pop into my mind is 'burden' is this societies projected view that adults with ID are a burden?? Is it this felt sense of being a burden that service users refer to when they say they do not want to bother staff? Staff also feel that no one really cares about them but is it that no one really cares about the job they do as long as someone is looking after adults with ID society does not have to worry???? Why is it that adults with ID are considered a problem? Why can we not see the many other aspects of self and identities they hold?

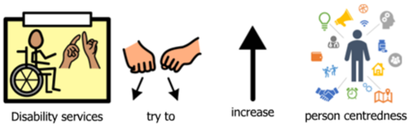
Appendix P: Easy-read findings



This study found that:

Adults with ID don't have choice or control over their lives.

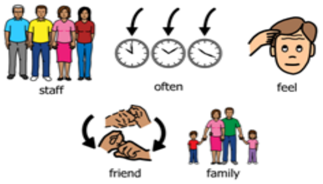
Adults with ID are treated differently.



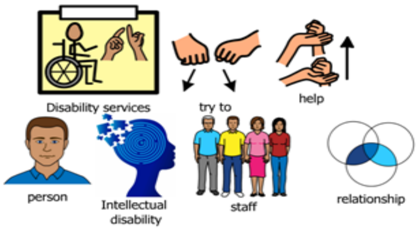
Disability services need to improve developing person-centeredness.

This study found that:

The relationship between service users and staff is really important.

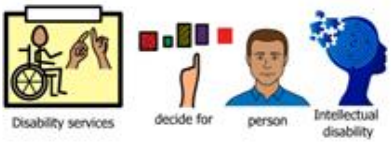


Staff often feel like friends or family.

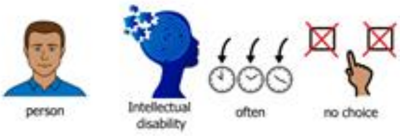


Disability services should pay more attention to this relationship.

This study found that:

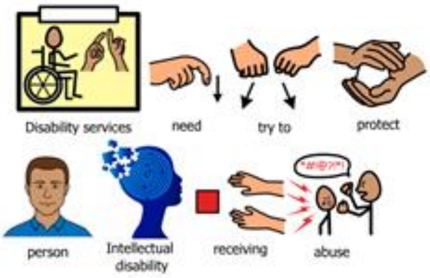


Disability Services make decisions for adults with ID



The adult with ID often does not get a choice.

Disability services think more about quality of care and not enough about the quality of life of adults with ID.



Disability Services need to protect adults with ID from experiencing poor or abusive care practices.