

An Exploration of Staff's Support with Adults with Autism in Occupational Engagement in their Daily Lives



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Declaration

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Summary

This study explored staff members' perspectives on support of adults with autism in occupational engagement and participation in communication, social contact, hobbies and interests and daily routine in an Irish autism specific disability service. The research objectives facilitated the exploration of factors affecting staff in their support of adults with autism.

The qualitative descriptive method (Sandelowski, 2000) generated data through semi-structured interviews (N=8). Purposive sampling (Mason, 2002) delivered three day service staff, three residential service staff, and the two garden participants.

Braun and Clarke's (2006) thematic analysis was applied resulting in five main themes; day to day practice of support; how staff support the person to engage such as communication and tuning in. The third theme relates to relationships within the service and their importance to the day to day work. The fourth theme related to staff's role and the emotional labour involved in the work. Organisational culture, the impact of regulation and management styles was the fifth theme.

The findings of this study highlight the skilled work of the participants in the exploration of and support for the person's own goals. Their skilled ability in quality interactions through the process of attunement was demonstrated. The participants presented as person-centred in their thinking, whereas they considered that the system is not. In particular, the residential service environment impacted on staff's ability to achieve person-centred care.

The results highlight the value that participants hold on relationships with, for and by service users in maintaining friendships and having a meaningful experience of community. Relationships between frontline staff and their management were critiqued. A disconnect between what is being measured as quality and participants' experiences of quality in residential services is critical of regulation approaches. The burden of administration tasks on staff was considered to impact negatively.

The importance of reflection, supervision and emotion management was highlighted in the results of this study, prioritising the personhood frontline staff. Good leadership from management was considered to be essential to achieve person-centred care.

Future research should explore the support given to adults with autism from their own individual perspective. The meaning of community to the individual with autism and their experience of community is a recommended area for future research. Finally, research is recommended to explore the actual level of paperwork burden on staff in organisations and whether it is getting in the way of people receiving high quality support services.

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Firstly, I extend my sincere thanks to Dr. Siobhan MacCobb for her unwavering encouragement and support throughout this process. Siobhan has not only been my mentor in research but also in practice, which has been invaluable to my professional development.

“For me, a mentor is a person who leads, who inspires, guides and challenges me to think, gives wise counselling, shows commitment to professional excellence, and whose personality is reflected in their own professional beliefs and values... The mentors in my life are valued for their honesty and wisdom and their belief in my skills and abilities. They have presented challenges to my thinking processes and encouraged me to extend myself beyond traditional expectations” (Christy, 1999).

I would like to thank my organisation for supporting this piece of research and all who contributed to its completion. In particular, I want to thank Peter Byrne, for his big heart and warm smiles which provided continuous encouragement throughout the process. Peter’s curious nature, open mind and inspiring commitment to people who require support from services, will stay with me throughout my career.

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Chapter One – Introduction

1 Introduction

Yerxa and colleagues (1989, p. 6) originally defined occupational science as *“the study of the human as an occupational being including the need for, and capacity to engage in, and orchestrate daily occupations in the environment, over the lifespan”*. This definition lays the foundations of this study where all people are understood as occupational beings, with an innate drive to engage in meaningful occupation, within the context of their environment. Occupational science establishes the philosophical basis of this research study, alongside the theoretical underpinnings described below (Section 1.3).

Occupational engagement and participation are therefore the methods of supporting people to have meaningful lifestyles that promote health and well-being.

In light of this philosophical basis, the condition of autism is not considered a central concept in the study. Autism Spectrum Disorder (ASD) is defined and discussed with relevance to the person’s occupational engagement.

The purpose of this study was to explore staff member’s support with adults with autism in occupational engagement in their daily life. The participants of the study are staff members working in an autism specific disability service in Ireland. The age range of the people with autism receiving a service from the organisation is from 18 years of age, to those in their 70s. The profile of the people with autism is equally as broad, spanning across the entire autism spectrum.

This chapter will be divided into two parts, each providing context to the study. Part one will offer a description of the theoretical foundation of the study, with an in-depth discussion framed within the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007).

Part two will provide context on the study site as existing within the current Irish policy environment. The aims and objectives of the study along with a description of the researcher’s background, assumptions and experience of working in the service are presented, as are the limitations of the study and a definition of terms.

Part One – Supporting Occupational Engagement

The study of people as occupational beings has informed our understanding of the relationship between occupational engagement and health (Wilcock, 2005). An important concept discussed within occupational science is that of occupational justice, presented below as applied to people with autism, when accessing supports from disability services in Ireland.

1.1 Occupational Justice

An “occupationally just world is envisioned as one that would be governed in a way that enables individuals to flourish by doing what they decide is most meaningful and useful to themselves and to their families, communities, and nations” (Wilcock & Townsend, 2009, p. 330). Since occupations are core to human existence, restrictions to participation in occupations are a matter of justice (Townsend & Wilcock, 2004).

Townsend and Wilcock (2004) appreciate that people have differing occupational needs, strengths, and potential which require differing forms of enablement to flourish. Supporting people with autism is an individualized practice, where some individuals require complex levels of support, others require little or intermittent support and others do not want or need any on-going support (D'Astous V. , Manthorpe, Lowton, & Glaser, 2016). Much of the literature around ASD and occupational therapy focuses on child-based interventions, with emerging literature in the area of transitioning to adulthood and adult support services (Thompson, Bolte, Falkmer, & Girdler, 2018; Havlicek, Bilaver, & Beldon, 2016; Senland & Higgins-D'Alessandro, 2016).

Within a western context where individual autonomy is exerted within an individuals' environment, occupations are seen as the practical means through which individuals may exert citizen empowerment, choice, and control (Townsend & Wilcock, 2004).

Occupational therapists should base practice on a thorough understanding of occupation and an understanding of the role occupation plays in the well-being of individuals (Dickie, 2009). Thus, Whiteford's (2000) statement is relevant in a disability service setting, that occupational therapists should embrace occupational justice and exert more time and energy into influencing social and institutional policies and structures that may provide individuals with their basic human need and occupational right to “do”.

1.1.1 Occupational Deprivation

This form of occupational injustice involves being excluded from engaging in meaningful or necessary occupations due to factors outside of the individual's control (Whiteford, 2000). These external factors may be social, environmental, economic, geographic, historical, cultural, political or interpersonal (Wilcock, 2006).

Arendt (1978), a political theorist of the 20th century, maintains that there is one universal right based on meeting the criterion of being human, and which is not governed by nationality, race or any other criteria, in her own words, is 'the right to have rights'.

Occupation is not officially recognised as a human right in the UN Universal Declaration of Human Rights (United Nations, 1948). The World Federation of Occupational Therapists state that the profession has a role in raising society's awareness of the broader view of occupation and participation as a human right. Law (1991) was one of the first occupational therapists to bring attention to the inequalities of opportunity for participation experienced by people with disabilities. Respecting human rights of people with autism, within a framework of collective responsibility may help maximise autonomy, social inclusion and well-being (D'Astous, Manthorpe, Lowton, & Glaser, 2016).

1.1.2 Occupational Alienation

Occupational alienation occurs when an individual experiences' prolonged "disconnectedness, isolation, emptiness, lack of a sense of identity, a limited or confined expression of spirit, or a sense of meaninglessness" (Townsend & Wilcock, 2004, p.80). It may occur when an individual is limited or forced to participate in occupations that are purposeless (Stadnyk et al., 2010; Wilcock 2006). The American Psychiatric Association (APA) (2013) suggest that people with intellectual disabilities, which likely includes people with autism, may be predisposed to occupational alienation due to an inherent need for on-going support with daily activities.

Mahoney, Roberts, Bryze and Parker Kent (2016) found that individuals experienced occupational alienation due to staff members' struggles with engaging with more than one person at a time. Therefore, those individuals were unable to access activities while waiting on assistance.

1.1.3 Occupational Marginalization

Occupational marginalization involves being excluded from participating in occupations due to invisible social norms and expectations about who should participate in what occupations, how, when, where and why (Stadnyk, Townsend, & Wilcock, 2010). It is experienced by individuals or groups who are not afforded the choice to participate in valued occupations (Stadnyk, Townsend, & Wilcock, 2010) and by those who are not afforded the opportunity for decision-making (Townsend & Wilcock, 2004). Autism can be seen as a different way of interacting and relating to the world, where D'Astous, Manthorpe, Lowton, & Glaser (2016) state that it is not autism that limits a person's societal engagement, but rather society's exclusionary attitudes and structures. Society should work to remove marginalising barriers to people with autism by adjusting environmental spaces and developing supportive services to enable people to be part of society. Thompson et al., (2018) asserts that policies and services should focus on the strengths of people with autism to maximise their participation in independent living, higher education, and employment. They further suggest that interventions targeting environmental factors, using person-centred and individualised approaches could be effective in improving the person's participation in adult life.

1.2 Occupational Engagement

After reviewing the literature on occupational justice, the concept of occupational engagement is introduced. The relationship between occupational engagement and occupational identity is then discussed.

Occupational engagement is an essential part of occupational therapy practice.

“Achieving health, well-being, and participation in life through engagement in occupation” is the essence of occupational therapy (American Occupational Therapy Association, 2014, p. S4). The concept of occupational engagement involves engagement in all kinds of everyday activities and relates to the degree to which a person experiences a sense of meaning from occupation, has a variety of occupations that create a daily rhythm, initiates occupations, interacts with other people and acts independently (Tjornstrand, Bejerholm, & Eklund, 2015).

Meaning, choice and motivation are important aspects of occupational engagement (AOTA, 2014). The CMOP-E broadens our view of occupation for people with autism, critically beyond performance, as the model tells us that a person may be actively, passively, constantly or sporadically involved (Townsend & Polatajko, 2007). We then acknowledge the importance of a person with autism engaging in an occupation, regardless of their level of performance.

An individual being present for an activity, is different from an individual engaging in an occupation. Therefore, occupational therapists should recognize patterns in how specific populations, such as adults with autism, express occupational engagement (Mahoney, Roberts, Bryze, & Parker Kent, 2016).

Services that provide support to people with disabilities during safe, purposeful activities often neglect addressing co-occupation (i.e. mutual engagement in a shared occupation), adapted occupations and personalized choices (Channon, 2014; Teitelman, Raber, & Watts, 2010; Mahoney & Roberts, 2009). Mahoney, Roberts, Bryze and Parker Kent (2016) found that social support from staff members was a key factor to individuals' level of occupational engagement, by presenting adapted occupations with objects, clear expectations, structure, and environmental supports.

In addition, as individuals with autism leave the school system, they are at risk of losing social supports such as clubs, sports and activities that provide structured opportunities for community engagement and participation (Myers, Davis, Stobbe, & Bjornson, 2015). It is suggested that from adolescence to adulthood, individuals with autism rely on others to help organize social and community opportunities (Myers, Davis, Stobbe, & Bjornson, 2015), placing them at risk of occupational marginalization if no such advocate is present. Thus, occupational therapists should address this occupational injustice and perhaps empowerment could be used as a means for occupational engagement (Hultqvist, Eklund, & Leufstadius, 2015).

Occupational engagement involves the transactional interaction of mind, body, and spirit (AOTA, 2014), as reflected in CMOP-E. In 2007, engagement was added as an important consideration in the model (Turpin & Iwama, 2011). The CMOP-E emphasized how a person can be fully engaged in an occupation without ever performing it (Turpin & Iwama, 2011). Perhaps for people with autism, who may find it challenging to complete necessary or chosen occupations, it is the engagement and participation that is more important.

1.2.1 Occupational Identity

Humans are occupational beings, finding meaning in their lives through what they do (Davis & Polatajko, 2011), and over time, a person's occupational identity is formed by what they do. This identity, formed from experience, is a sense of who people are and who they wish to become, as an occupational being (Forsyth, et al., 2014). Williams (1992) advocates for carers providing support to people with autism, to look beyond the label and focus on the person as a human being. Williams contends that if practitioners turn a person with autism into a case, their identity will be lost. We must see people with autism, as people first. Shakespeare and Watson (2002) assert that people with disabilities may identify, at different times as a person with a particular impairment, as a disabled person, or by their particular gender, ethnicity, sexuality, occupation, religion, or football team.

Carl Roger's held that the best way to understand an individual is to use their own 'self-view' (Cole & Tufano, 2008). How people see themselves and the groups or communities they belong to, can be strongly influenced by other people's reactions to their behaviour,

beliefs and ideas. Occasionally, staff members can offer opinions about how someone should think or feel about their disability, which can have a profound effect on their identity and sense of self (Alaszewski, 1995). Temple Grandin's life story illustrates this, as in the 1950's, her mother persevered against much pressure to institutionalise Grandin and insisted on educational opportunities to encourage her creative and artistic talents. Without her mother's belief, Temple Grandin would never have gone to school, or higher education, let alone become a university professor, the subject of biographies and a movie, known worldwide (Hughes, 2017).

Voh (1993) is convinced that the experience of belonging is at the heart of the considerable pain there is in relation to disability and is likely close to the heart of what it means to be a human being. She believes that we all need 'a place to stand', to belong and that our fundamental beliefs about who we are can influence how we see the world. For people who cannot independently portray their occupational identity and sense of self, Brooker (2003) states that it is crucial that a person's sense of self is held with the relationships they experience, which allows an expression of their occupational identity. Grandin (2006, p. 162) recognises this need for connection and support to engage, *"I strongly recommend hobbies and careers where common interests can be shared. Mentors who can nurture talent can help students become successful"*. Occupations, such as special interests for people with autism, connect them with others in their lives and gives them a sense of continuity (Whiteford, 2007). Recognising the spiritual core of a person's identity, their beliefs about who they are and what occupations have meaning for them, is practicing in a way that is truly person-centred (McCormack & Collins, 2012).

1.2.2 Participation

The construct of participation comprises “what the person can do, wants to do, has the opportunity to do and is not prevented from doing” (Mallinson & Hammell, 2010, pp. S29-S33). It involves engagement in meaningful activities that is maintained by a person’s capabilities in their environments. Environments provide opportunities for participation, that depend on the individual’s ability to respond and make use of those opportunities (Matheson & Bohr, 1997).

People with autism often have difficulties in social engagement, stemming from impairments in social interaction and communication skills (APA, 2013). Service providers must recognise the participation patterns of the people they support and factors affecting participation in order to identify targets for intervention related to social engagement (Chen, Bundy, Cordier, Chien, & Einfield, 2017).

Understanding the influence of cultural context on daily participation will improve professionals’ cultural competence for delivering services to individuals from diverse backgrounds (Chen et al., 2017) and indeed within the culture of disability services. Chen et al., (2017) found that people who presented with fewer ASD symptoms were less likely to engage in social interaction, suggesting that they may be more aware of their social difficulties, perhaps perceiving themselves as socially incompetent, thus being less inclined to interact with others. Supporting social participation is important to help people with ASD form relationships and establish natural support networks, which contributes to quality of life. It was found that social participation, social functioning, and quality of life for adults with autism are enabled through informal social support from social networks, participation in social skills and support groups (Chen et al., 2017).

Chen et al., (2017) found high levels of unemployment and underemployment among adults with autism, and in some cases, up to half of participants had no consistent daily activities or occupations, which Renty and Roeyers (2006) related to a lower quality of life.

1.3 The Theoretical Foundation of the Study

The theoretical lens chosen for this study was the Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2007). This model aims to highlight the relationship between person, environment and occupation, and is based on

the assumption that occupation is the *“bridge that connects person and environment”* (p.23). The model depicts the person as embedded within the environmental context, which guided the researcher to pay attention to the unique cultural, institutional, physical and social aspects of each person’s environment which can afford occupational possibilities.

The CMOP-E was developed in line with the values of person-centred practice and the humanistic principles of Rogers and Abraham Maslow. It places the person at the centre of its model, recognising the components of the whole person as bound together by the core of their being, spirituality (Cole & Tufano, 2008).

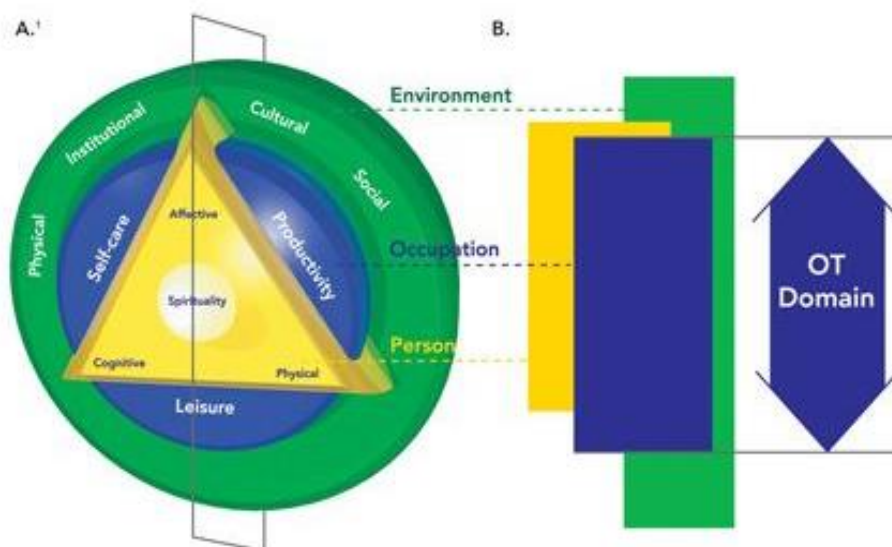


Figure 1: The Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2007)

The CMOP-E marks a shift in occupational science and occupational therapy literature, guiding therapists to look beyond occupational performance and ‘doing’, and to pay more attention to ‘being, becoming’ (Wilcock, 1999) and engagement (Doble & Santha, 2007). This shift in thinking influenced the researcher’s lens when thinking about people with autism and how they are supported, where often the being, becoming and engagement is more important than performance. The model prompted the researcher to ask questions such as, how can support with occupational engagement impact on a person’s sense of self and identity, questions around occupational balance and what, within a disability service setting, might influence the person’s choice of occupation and participation (Reilly,

2012)? It guided the researcher to recognise the spiritual core of people with autism and how this is recognised, or not, by the organisation and more importantly, it's staff. Furthermore, the researcher reflected on the spirituality of staff, and how their environmental context impacts on their own self, thereby influencing the support provided to the person with autism. The CMOP-E allowed the researcher to organise her reflections on the environment of the disability service setting throughout the research process.

The following exploration of the Person, Environment and Occupation will be framed using CMOP-E (Townsend & Polatajko, 2007).

1.3.1 The Person

"Life with autism brings its challenges. The condition impacts on how people go about their day to day life, in a way others take for granted, indeed everything from going to school or work, making friends or even just going to the supermarket presents different hurdles" (AslAm, 2017). People with autism can experience lifelong challenges with full participation in social and leisure activities and contexts, which can be linked to core difficulties in social communication, restricted repetitive behaviours and sensory processing difficulties (APA, 2013).

The vast body of research on autism exists in the absence of a single biomedical marker to identify the presence of autism. The diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders, version five (DSM-5) (APA, 2013), is critical for diagnosis so people receive appropriate supports (Section 1.5.1). The DSM-5 is a useful tool to outline challenges that people with autism face in their daily lives, however, it views people in terms of deficits. Silverman (2008) opposes its view, stating that we must see autism as a difference, not a disorder that comes with deficits and impairments.

Williams (2009) urges people to look beyond the label and focus on the person, stressing that the person comes before any label. She advocates that we should never lose sight of the person and their individual character and personality, because if we lose sight of it, they will too. As no two people with autism are the same, or present with the same strengths and challenges, staff must be embedded in supporting individual needs, *"It is*

impossible accurately to sense the perceptual world of another person unless you value that person and his world – unless you in some sense care” (Rogers, 1975, p. 7).

A focus which places people with intellectual and developmental disabilities as the experts of services and supports, is a priority (Hewitt, Agosta, Heller, Williams, & Reinke, 2013).

Unless we recognise the expertise that personal experience brings, such as the experience of being autistic, it is unlikely we will spend time trying to understand a person’s situation from their own perspective (Repper & Perkins, 2003). In order to enable adults with autism and their families, to not only meet their basic needs and wants, but to blossom, individualized and autism-informed services are essential (Herrema et al, 2017). The importance of appropriate support services is well documented in the literature (Renty & Roeyers, 2006; Gupta & Singhal, 2005; Hare, Pratt, Burton, Bromley, & Emerson, 2004).

The AslAm community, a charity campaigning for needs of people with autism in Ireland, strongly believe in providing people with autism with the tools to reach their potential and that *“for too long those with autism have been told what their needs are and what to do about them”* (AslAm, 2017).

Within health services, the traditional focus on deficits means that it is easy for the person and staff supporting them to lose sight of the person’s strengths and resources. If staff are unable to see the person’s gifts and abilities, then it will be impossible for them to foster the hope necessary to enable the person to use their gifts (Repper & Perkins, 2003). This perspective is upheld within occupational therapy literature, where Molineux (2004) calls for occupational therapists to focus on people’s strengths rather than their deficits. If an individual with autism, is to build a meaningful and valuable future, then it is their skills and abilities that must be the building blocks with which staff see potential to be developed and explored (Repper & Perkins, 2003).

In general, people with disabilities, especially people with autism, are given less opportunity to be self-determined than their peers without disabilities (Wehmeyer & Shogren, 2008). The social disability characteristic of autism may pose difficulties related to the components of self-determination, such as communicating ideas and solutions to problems (Channon, Charman, Heap, Crawford, & Rios, 2001), as well as setting and working on multiple goals (Ruble & Scott, 2002).

Viewing self-determination as a lifelong process can enhance the concept, using developmental trajectories of specified elements of self-determination to guide people through a continuum of activities to build capacity, opportunity, and competence throughout a person's lifetime (Wehmeyer & Palmer, 2000). People with autism can develop the skills necessary for self-determination, when appropriate supports for social and communication needs are provided (Wehmeyer & Shogren, 2008; Fullerton & Coyne, 1999).

A person-centred, relationship-based approach is recommended when supporting adults with autism (Koenig & Kinnealey, 2010). Person-centred outcomes require staff to engage in learning before acting, in order to understand the person's prioritised outcomes. Staff need to engage in a process where they listen, observe, ask, discover, question, and redirect, which is conceptually simple but subtle in practice (The Council on Quality and Leadership, 2018).

1.3.2 The Occupation

Within the CMOP-E, occupation is thought of under three components, self-care, productivity, and leisure, which will be discussed together for the purposes of analysing the literature.

Literature highlights that people with autism often have challenges with day to day activities, such as employment, socialization, communication, independent living and having friendships (Gotham, et al., 2015; Lawrence, Alleckson, & Bjorklund, 2010; Howlin, 2003). Occupation encompasses all activities of everyday life for all people, but has a meaning component, which is personal and unique to the individual (Townsend & Polatajko, 2007). Meaning can evolve from engagement in occupation and occupation can evolve from meaning (Hasselkus, 2011).

The World Health Organization (2001) regards full participation in daily activities and routines as a fundamental indicator of health and functioning. Adding to this, Doble and Santha (2007) propose that health and well-being are enhanced when people experience occupational well-being. For those with autism, an experience that has been likened to living in an inhospitable non-autistic world (Williams, 1992), the experience of occupational well-being may be difficult to reach without appropriate supports.

An under-researched consequence of a lack of engagement in meaningful occupation, is the phenomenon of boredom. Boredom is elusively defined but has been described as “*a state of relatively low arousal and dissatisfaction, which is attributed to an inadequately stimulating situation*” (Mikulas & Vodanovich, 1993, p.3). There is a crucial relationship between the person and the activity which influences the onset and experience of boredom. The term activity is used, as opposed to occupation, as occupation is closely linked with a personal sense of purpose, engagement, value and meaning, experiences whose absence result in boredom (Molineux, 2004). Occupational therapists and support staff, therefore have a role in getting this balance of stimulation right for the people they support, a concept coined by Csikszentmihalyi (1992) as, flow.

The most important characteristic of flow is the balance between the challenge of the occupation and the skills of the individual, resulting in a sense of control over what one is doing and being so absorbed in the occupation that one may lose self-consciousness and forget worries or negative thoughts. This is a starkly different experience to that of boredom, which when intense, the person seems to want to escape either the source of their boredom, or the state of being itself (Molineux, 2004). An appreciation of boredom and flow, therefore is important for staff, as they are often scaffolding and facilitating engagement for people with autism. Particularly relating to this population, it is important to know that repetitive tasks are not necessarily boring, but studies have shown that the meaning of the task is more important than its monotony (Perkins & Hill, 1985).

Participation in meaningful and purposeful activities has been shown to enhance life satisfaction (Wilcock, 2005) and to positively impact a person’s health and wellbeing (Law, Steinwender, & Leclair, 1998). Setting and attaining meaningful goals are important components of self-determination for people with various developmental disabilities. However, it is possible that individuals with autism are not always given adequate opportunity to learn the necessary skills to set, attain and practice meaningful goals (Carr, Moore, & Anderson, 2014). Meaningful goals set by, or with the person with autism, can contribute to fostering a sense of self-efficacy. If the person engages in occupations that they had not previously believed they could engage in, either due to their own perception of their disability, or that of the organisation, a sense of self-efficacy grows (Christiansen, 2004).

Parents of people with autism have stressed the importance of using the person's special interests and strengths as a way to foster motivation, creating positive experiences and building self-confidence (Thompson et al, 2018). Autistic people's strengths and abilities should be focused on, within an environment that enables occupational engagement, providing affirmation that they are worthy human beings (Rebeiro, 2001).

1.3.3 The Environment

Occupations are performed everywhere. The environment is not only a context for occupational performance, but it can shape occupational choices, influence health and well-being, and impact on social inclusion or exclusion (Townsend & Polatajko, 2007, p. 48). Having autism, impacts on how a person communicates and relates to other people and the world around them. Everyday sensations can be experienced at intolerable levels, or seem not to be noticed at all, affecting a person's ability to engage with the environment effectively and to participate in everyday activities (Bagby, Dickie, & Baranek, 2012; Dickie, Baranek, Schultz, Watson, & McCornish, 2009)

1.3.3.1 Social

In adulthood, individuals with autism have poor social outcomes. They are less likely than their typically developing counterparts to live independently away from home, to marry or have friendships, to complete college courses or to gain employment (Howlin, Goode, Hutton, & Rutter, 2004; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Addressing social isolation, or autistic aloneness as Frith (2003) terms it, should be a priority for service providers who have an opportunity to create a social environment and opportunities for those with autism (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). In a study looking at participation in daily activities by adults with autism, the environmental barriers to social participation were identified to be no transportation, the attitudes of others, having no one to do it with, and never having the chance (McCollum, LaVesser, & Berg, 2016).

Empowering young adults with autism to make social connections, take social risks, and conquer their fears of social situations, requires targeted approaches to offer support, tolerance and compassion for communication blunders (Gray, Keating, Taffe, Brereton, & Einfeld, 2014; Pinder-Amaker, 2014; Hume, Loftin, & Lantz, 2009). Asking them to tell

their own story, to identify goals, and to engage in a discussion about the barriers to progressing socially (McCollum, LaVesser, & Berg, 2016) has been supported in the literature and termed an “inside-out perspective” (Koenig & Kinnealey, 2010, p. 244). This highlights the need for support services to scaffold a person’s social environment.

The school environment can provide structure to the young person, where they receive supports and services, but once the person leaves school, there is a “service-cliff” (Havlicek, Bilaver, & Beldon, 2016; Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). While discussing Temple Grandin’s book, *Thinking in Pictures*, Oliver Sacks states that “we almost always speak of autistic children, never of autistic adults, as if such children never grew up, or somehow mysteriously spirited off the planet, out of society” (Grandin, 2006). This is problematic, as although the need for services and support remains or even grows, support options for adults are limited (Bishop-Fitzpatrick, Minshew, & Eack, 2013).

Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher (2016) report that in Pennsylvania, social skills training was one of the most important missing support services, directly impacting on the person’s social communication and interaction needs. Social skills training is critically important in service provision for adults, especially given the difficulty adults with autism have in finding and maintaining employment (Roux, et al., 2013). It is imperative to recognise that these adults need support in advocating for themselves and connecting socially after school (McCollum, LaVesser, & Berg, 2016).

In addition, the participation of people with disabilities is affected by social attitudes they experience directly and by those they perceive to be held about people with disabilities in general (Garcia, et al., 2015).

1.3.3.2 Cultural

“The battle against autism is a big one and if no-one expects you to be able to climb a mountain, then maybe you wouldn’t even consider doing so, nor look for the tools with which to do so. My philosophy is that, it is not everyone who is a good mountain climber but that with the right coaching, everyone is capable of taking a few steps more than they might if not challenged or expected to do so” (Williams, 1996, p. viii).

Many people with autism live within residential care environments, an environment where cultural aspects may impact on the person's opportunity for choice and autonomy (Iriarte, Stockdale, McConkey, & Keogh, 2016). It has been found that an increase in choices in normal everyday tasks among residents of a Long-Term Care facility is related to a positive perception of quality of life, particularly when the choices relate to common tasks such as eating and self-care (Duncan-Myers & Huebner, 2000). In a residential setting, occupational choices available to people are influenced by opportunities, resources, and personal and social circumstances (Riley, 2012). For people with autism living in residential settings, one might be told what time to get up, what to wear, when to eat and when to engage in one's activities, as the routine of the house must continue. But what if we addressed the routine of the person, rather than the residential house? As the regulator of residential services, the Health Information and Quality Authority (HIQA) asserts, the residential house is the person's home and the person is a citizen, with the right to choice. In the "Nothing ventured, nothing gained" document on risk (Department of Health, UK, 2010, p. 17), one participant said, *"carers are the most important people in the world, but there are carers and keepers – the latter try to assume total responsibility for your life, often prematurely"*. Rebeiro (2000, p. 13) comments that this change in perspective and in routine, may require support staff to allow practice be guided by "client-visions", adopting a social advocacy role to tackle institutionalised practice and allow occupational engagement to become a reality (Rebeiro, 2000, p. 13).

There is a lack of research on how to improve engagement in activities within a residential setting (Cook, Mundy, Kilaspy, Taylor, Freeman, Craig et al., 2016). However, when analysing mental health hospitals and residential settings, Cook et al. (2016) identified environmental barriers, many at a societal and institutional level, that can limit a person's engagement, including service expectations, highly scheduled routines such as strict activity schedules, rigid meal times and poor staff to resident ratios. Other barriers include the value that is placed on prioritising medication and record keeping, impeding staff's flexibility in giving time to support engagement both within the residential setting or supporting a person to access the community (Cook, et al., 2016). In addition, King (2018) examined data from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) and found that the physical environment within the home and local community has a significant impact on the person's ability to engage in self-care, productivity and leisure activities. King (2018) recommends further research utilising an

occupational perspective, focusing on the occupational engagement of a person with ID and the supports available to them.

Research on intellectual disability services has shown that staff provide support less than 10% of the time, or less than 6 minutes per hour (Mansell, Beadle-Brown, & Bigby, 2013; Felce, Lowe, & Jones, 2002b; Felce & Perry, 1995). For those with higher support needs, levels of assistance are usually even lower (Beadle-Brown & Hutchinson, 2016). Research states that on average, people with severe disabilities spend at least 50% of their time not engaged in any meaningful activities or interactions. Person-centred active support was developed to combat this culture within organisations, switching from a mindset of *doing for* to *doing with*, and placing the person at the centre of everything staff do, not sitting on the periphery waiting for staff to have time for interaction (Beadle-Brown & Hutchinson, 2016). Love and Kelly (2011) write on this topic in the area of dementia nursing, asserting that a different mindset is required for staff to look beyond the short-term task accomplishment to the long-term goal of facilitating well-being. They assert that although a holistic approach to care is instilled early in a nurses' training, it is too easy for the mentality of institutional efficiency to creep into practice. Perhaps this is transferable to the current climate of people with autism living in residential settings that are governed and inspected by HIQA, accompanied by increased bureaucracy.

Molineux (2004) writes that some environments generate more feelings of boredom than others, and that this experience, if prolonged, can have a negative effect on an individual's health and well-being. Hence, boredom should be a consideration for staff working in restricted or unstimulating environments, such as residential accommodation, inpatient wards and disability services (Molineux, 2004). However, non-institutional living environments may also restrict occupational opportunities or choices, where people may not have the means to fill their time in a meaningful way, resulting in boredom (Molineux, 2004), such as the physical and social environment that may be created around a person with autism, as a result of the changing policy landscape of disability services in Ireland. Those in family homes and in supported living can be bored too. Therefore, support staff need to reflect on the sometimes-simplistic idea of people living on their own, and address risk of boredom.

Conversely, it is not only service users that may experience boredom as a result of the environment, but staff too. Fisher (1993) describes how organizations that impose

inflexible rules, reducing the amount of stimulation and variety in the workplace, are more likely to cause boredom amongst staff. Furthermore, the greater the external control in performing tasks, the greater the chance of workers experiencing boredom.

In a disability service setting, support staff make up a large portion of the person's social environment and may have an effect on the person, as described by Chadwick (1997b, p. 23), *"Forever harping on disasters, dangers, deficits and dysfunctions does not encourage the strength needed to overcome the problems that present themselves"*. He argues that a continual focus on the negative aspects of a person's condition or disability, has a destructive impact on the person and that such an attitude, within mental health, can eliminate any hope that recovery from mental illness is even possible. Without hope, there can seem little point in trying to conquer difficulties.

Koca-Atabey (2013), a researcher within disability studies, suggests that while impairments may be unchangeable, a person's experience of being disabled changes according to environmental context. So, if those supporting the person with autism, have hope, and believe that the person has potential, abilities and strengths, perhaps this could influence the occupational engagement opportunities for the person. Voh (1993) describes how after examining her own thoughts and assumptions about her child with cerebral palsy, she realised her sadness was coming from a reality that she had previously accepted as the truth, that disability equals tragedy, a life of sadness and coping as best one can with the terrible reality. However, when she began to change her behaviour and beliefs, she began to believe that disability was a natural part of life and she was free to interact with her child and her disability, separate from the impulse to try and make her better.

Rebeiro (2001) concluded that a cultural environment which offered people opportunity, choice, affirmation as persons of basic worth, supportive of their being needs, and which offered a sense of belonging, were essential to a persons' confidence to initially engage in occupation and subsequently to their health and well-being. Support staff to people with autism can indeed establish an affirming environment, by eliminating any perceived or real power hierarchies (Townsend, 1998) within their relationship, including deferring authority, handing back power to those who have experience of the condition (Whalley Hammell, 2013).

Laursen and Yazdgerdi (2012) assert that while people with autism have unique strengths and difficulties, they have the same universal human need for belonging, mastery, independence and generosity as neurotypicals. They facilitate college support programs for young people with autism in America, focusing on academics, social skills and independent living. Their services are intentionally designed with a focus on relationships, where they use 'Talking Circles' and 'Support Circles' to support people to engage and practice reciprocal interactions in their everyday life. The catalyst for a sense of belonging that is used by this group is, relationships, *"people helping people to develop their sense of significance in relationships"* (p. 46). Their work demonstrates that people with autism crave belonging just as others do, illustrated by one of their students, *"For my entire life, I have searched for a sense of belonging – for friends my own age, a club, or a community where I can be myself and feel at home"* (p. 45).

Furthermore, the Australian 'We Belong' study (Aspect, 2013) found that adults with autism do not necessarily 'prefer their own company', with some of the participant's happiest memories of education and the workplace centred around friendships, social interactions and collegiality. Many participants reported they would like to switch their current housing arrangements from living alone to living with others. Interestingly, upon reflecting on their hopes for the future, the participant's desire for social and relational fulfilment outweighed career ambitions, health ideals and other self-focused aspirations (Aspect, 2013). With rich opportunities to experience relationships, with patient and understanding people, and with the courage to take risks and learn new skills, people with autism can find belonging (Laursen & Yazdgerdi, 2012).

1.3.3.3 Physical

Many people with autism require individualised environments, often unbecoming to neurotypical people, as shown by Duignan and Connell (2015). Families reported having adapted home spaces, creating a care environment, a partial institutionalisation of the home where the atmosphere of peace, relaxation and spontaneity for family members was lost. In a residential setting, Lowe, Gaudion, McGinley and Kew (2014) involved people with autism in design research, supporting them to be active participants in designing their living environments, in order to reduce triggers of anxiety, maximise comfort and create an enjoyable and meaningful home. This project was a process of creation that put the person at its heart and found environmental solutions around them.

The residential environment is an essential element of overall well-being and independence for people with autism. Adequate housing choices and supports for people with autism are critical components of community living and participation (Hewitt, et al., 2017). Hewitt et al., (2017) addressed the need for supports to be family and person-centred using strategies that are consistent with individual and family customs, values and daily rhythms.

The environment and occupation have an interesting, reciprocal relationship; the environment has an influence on occupation, and in turn, occupation has an influence on the environment (Townsend & Polatajko, 2007). Occupational therapists understand the futility of interventions focused solely on the person, contending that we must try to improve the circumstances of disabled people by inducing environmental change (Canadian Association of Occupational Therapists, 1991; Law, 1991). It would make sense then, for occupational therapists to *“give up power, acknowledge the political nature of our role, and work together with clients and others to resolve environmental problems”* (Law, 1991, p. 178).

1.3.4 Spirituality

The CMOP-E places spirituality at its centre, as the essence of the self. Frankl (1988, p. 40) asserts that “spirituality means uniquely and truly human”. For some, spirituality is a religious concept, for others, it is much less clear, being simply a feeling or sense of meaning (Townsend, et al., 2002).

Often, we do not know and are unable to articulate the meanings of events or relationships in our own lives, how difficult then it is to ascribe meanings of events and relationships, to other people’s lives (Hasselkus, 2011). When advising on teaching methods for children with autism, Roger and Dawson (2010, p. 109) discuss a child’s ‘spotlight of attention’, observed in the child’s behaviour when something is interesting, intrinsically rewarding and motivating. This tells the ‘more capable peer’, as Vygotsky (1978) termed them, that they need to be attentive and watchful to what is meaningful, indeed spiritual.

“Out of a person’s stories about the past comes the meaning of the present” (Hasselkus, 2011, p. 10). Another way then, to come to understand the meaning of a situation to a person with autism, is to learn about their life history and past experiences. Pitonyak (2009) advocates using storytelling in social care, claiming that a person’s story is connected to their spirit, by telling their story they stay connected to the deepest parts of themselves. After her breakthrough in communication, Carly Fleischmann stressed, *“I want people to understand that autistic people are people, and we all have an inner voice”* (Fleischmann & Fleischmann, 2012, p. 143). It is imperative then, that those supporting people with autism learn about their life history and get to know the person first. Love and Kelly (2011) advocate that nurses first find out what makes a person happiest each day, what they liked best about their lives at different ages, and had they ever won the lottery, helping to form a picture of the person’s life, with healthcare needs as a subset of the whole person.

Each person, despite capabilities or disabilities, is born with an authentic self, as Palmer (2000) stated, we are born with a life to be lived. As occupational therapists, we work together with people *“to let their lives speak, to enable the expression of their authentic selves, to help them experience their own deep inner beings in their daily lives”* through occupation (Hasselkus, 2011, p. 28). Wilcock (1999) believes that we should speak about occupation as a synthesis of doing, being and becoming. As mentioned earlier, Grandin (2006) advocates for people to focus on the person’s strengths, or special interests, as a means for their development. Perhaps support staff should heed this advice, allowing people with autism to do, be and become what they uniquely desire, as *“trying to be what others want us to be is a form of slow torture and certain spiritual death”* (Wilson Schaef, 1990, p. 29).

1.4 Interpersonal Relationships and Autism

“Loneliness is the only real disability... most of the people supported by our human service organisations are lonely. Profoundly lonely. And most of what we do in human services is secondary to helping people form and maintain meaningful relationships” (Mount, 2009, p. 7).

Mount (2009) asks staff within the human services ‘industry’ to take time to stop, to look, to spend time with the people in services, and question if they have love, *real* love, in

their lives. She believes that if you have people in your life who love you, you can get through anything. Whatever your disability is, you will be fine, if you have authentic relationships with others. The question is then, who are people with autism forming authentic relationships with? It is recorded in the literature that finding and maintaining real relationships is a priority for people with autism, *“I hope to find a lady who knows who and what I am... and accepts me just that way”* (Aspect, 2018).

Quality interaction is difficult to define and is further complicated when one person does not use or understand speech (Forster & Iacono, 2014). In examining the small body of research focusing on interaction between people with profound intellectual and multiple disabilities and their partners, Hostyn and Maes (2009) described four components important in interactions, sensitive responsiveness, joint attention, co-regulation and an emotional component. As Petry, Maes and Vlaskamp (2005) assert, quality of life is affected by the quality of interaction experienced by the person. Little attention in the research literature has been given to concepts related to social closeness or interactive relationships in which the goal is not the transfer of information, but rather just being with another person (Forster & Iacono, 2014). Such feelings of togetherness have been referred to as intersubjectivity, discussed in the literature around infant-parent dyad's (Beebe, Knoblauch, Rustin, & Sorter, 2005a).

Vygotsky maintained that much of a child's learning occurs through collaborative social interaction with a knowledgeable other. The skilful other, such as support staff, and the child, or person with autism, operate within the zone of proximal development, the difference between what the person can do for themselves and what they can do with the guidance of another. Scaffolding, a feature of social collaboration, is used by the knowledgeable other by carefully tailoring support for the learner so that they may benefit (Shaffer & Kipp, 2010).

Caregivers and infants mutually create chains and sequences of reciprocal behaviours that make up social dialogues. The caregiver is often working within the same modality as the infant, in the leadings, followings, highlighting's, and elaborations that make up their turn in the dialogue, generally carrying out close imitations of the infant's immediate behaviour. If the infant vocalises, the caregiver vocalises back. If the infant makes a face, the caregiver makes a face. The caregiver adds idiosyncrasy's and slight differences into these interactions so as to avoid repeats in communication (Stern, 1985).

The process of attunement is present within the mother-child dyad, where they have an inter-subjective relationship in which they are aware of and responsive to one another (Stern, 1985). Affect attunement is the execution of behaviours that express the quality of feeling of a shared affective state without imitating the precise behavioural expression of the inner-state. Attunement behaviours shift the emphasis of attention to what is behind the act, to the quality of feeling that is being shared (Stern, 1985). Given the largely non-verbal nature of these interactions and the early developmental age of the infants, this concept may have relevance to the interactions of adults with autism.

Forster and Iacono (2014) found that affect attunement is used by disability support workers with people with profound intellectual and multiple disabilities. They emphasise the importance of these very subtle interactions and how they demonstrate a way for two people to interact, regardless of the level of communication impairment, through tone of voice, facial expressions and postural changes. This research departs from a previous focus on inadequacy of support workers verbal communication skills with the person, and rather focuses on skill, or even a natural attitude that many staff use in natural, untrained interactions (Forster & Iacono, 2014). This is critical for people with autism, as it is through relation, meeting, connection that our lives are authentically lived (Hasselkus, 2011).

“For many autistic people, socialising can be challenging. There are no written rules or structures to follow, no points of reference or structure. This can cause huge anxiety for an autistic person. They may struggle to know how to behave or what to talk about in a social situation and so can feel uncomfortable” (AslAm, 2018). Research suggests that adults with autism often experience social isolation (Orsmond, Krauss, & Seltzer, 2004), with approximately one-half to two-thirds having no close friendships (Liptak, Kennedy, & Dosa, 2011; Whitehouse, Watt, Line, & Bishop, 2009; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, 2003; Howlin, Mawhood, & Rutter, 2000). It has been reported that when friendships do occur, they are less close and supportive than in the general population (Baron-Cohen & Wheelwright, 2003).

“The people on the spectrum who are depressed and unhappy often have no interests they can share with another person” (Grandin, 2006, p. 163). Grandin (2006) states knowing that things are missing in her life, but that her social needs are met through her work. She

advises parents of children with autism to stop fussing over their children's social lives and put the effort into their talents where they will naturally connect with others. She suggests that children with autism should be taught turn taking in groups so that as adults, they know how to work with others successfully, *"I think some of the high-functioning Asperger's people are having serious employment problems because today's society fails to teach social skills"* (p. 163).

1.5 An Irish Context

Simon Baron-Cohen et al., (2009) stated that over the past four decades, since autism was first identified, the global prevalence estimates for autism spectrum condition have been increasing steadily. However, the NDA (2017) state that it is unknown whether there is a true increase in prevalence, or if it is due to increased diagnoses and broadening diagnostic categories. In 1978, the consensus estimates for 'classic autism' was 4 in 10,000 (Rutter, 1978), and in 2009, autism was reported to affect approximately 1% of the population (Baron-Cohen, et al., 2009).

In Ireland today, estimates from the 2006 Central Statistics Office disability survey suggest a prevalence of 1.1% of the population (NDA, 2017). The most recent estimate of prevalence of school-going children diagnosed with autism is 1.55% (National Council for Special Education, 2016), suggesting that prevalence in adults is likely to be higher nowadays (NDA, 2017). While it was previously generally accepted that the male to female ratio was 4:1, it is now accepted that many females with autism are presenting differently to males and are in fact, going un, or mis-diagnosed (Middletown Centre for Autism, 2018; Kirkovski, Enticott, & Fitzgerald, 2013).

Approximately 50% of people with autism also have a concurrent intellectual disability (NDA, 2017). Due to the lack of specific statistics available on where people with autism are living in Ireland today, the researcher acknowledges the statistics available on the provision of services to people with ID who are registered with the National Intellectual Disability Database 2017 (HRB, 2018). The report concludes that the vast majority of adults with ID continue to live with their families with the aid of support services. The report acknowledges the need for additional supports such as respite services for these people as their caregivers age. However, between 2016 and 2017 in Ireland, there was a decrease in respite provision (HRB, 2018). This is the experience of the researcher within

the organisation involved in this study, where there are many people with autism in need of respite services but are not being provided with such services.

The HRB (2018) report that there is currently a high demand for services for school leavers with intellectual disabilities in Ireland, particularly in the areas of training and employment. In other countries such as America (Myers, Davis, Stobbe, & Bjornson, 2015; Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016), and Australia (Neary, Gilmore, & Ashburner, 2015), there is a reported decrease in the services received by people with autism, once they leave the school system. This service cliff is experienced by young Irish adults with autism too, where they lose the supports available to them in school, once they leave (NDA, 2017).

In Ireland today, there remains no standardised resource allocation system in place for assessing funding needs of an individual person for meeting their personal, health and social care needs (NDA, 2018). This is seen as one of the most significant challenges for organisations in implementing individualised funding for people in Irish disability services, coupled with the '*monumental difficulty*' of actually obtaining funding for the person, reported by a parent participant in Fleming's, McGilloway and Barry's (2015) research study.

1.5.1 Defining Autism Spectrum Disorder (ASD)

ASD is understood as a group of neurologically based developmental disorders characterized by difficulties with social communication and social interaction, and restricted repetitive patterns of behaviour, which may include sensory processing differences (APA, 2013). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) details a revised diagnostic criterion for autism-related disorders, as detailed in the following table (APA, 2013).

Table 1: Autism Spectrum Disorder Diagnosis Criteria, DSM-5 (APA, 2013)

Autism Spectrum Disorder Diagnostic Criteria (APA, 2013)	
A	<i>Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):</i> <i>1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.</i> <i>2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.</i> <i>3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.</i>
B	<i>Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):</i> <i>1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).</i> <i>2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).</i> <i>3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).</i> <i>4. Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).</i>
C	<i>Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).</i>

D	<i>Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.</i>
E	<i>These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.</i>

Table 2: Severity levels for autism spectrum disorder (APA, 2013)

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 “Requiring very substantial support”	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/ repetitive behaviors markedly interfere with functioning in all spheres. Great distress/ difficulty changing focus or action.
Level 2 “Requiring substantial support”	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/ repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/ or difficulty changing focus or action.
Level 1 “Requiring support”	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Cascio (2014) comments that given the constantly growing attention facing autism across the world, the social science perspectives are particularly important as they take a holistic view which situates autism within the larger sociocultural context. This perspective addresses the lived experiences of people with autism themselves through qualitative, ethnographic and collaborative research approaches. This view highlights the stance taken by this study, that each person with autism is a person first, who exists within their own unique environment. The diversity of people with autism is captured well by Stephen Shore's famous quote, *"If you meet one person with autism, you've met one person with autism"* (Hughes, 2012).

1.6 Description of Study Site

1.6.1 Institutional Environment

Three factors are discussed within the institutional environment of the disability service setting. They are ethos, model of service and funding model of the service.

1.6.1.1 Ethos

The statement of purpose for the autism-specific service involved in this research study was to deliver quality and safe services to embrace and support the unique individuality of persons with autism as valued members of society. The autism informed service aims to design individual person-centred services, facilitate family and community involvement, respecting the privacy and dignity of each individual and to live a low arousal philosophy. Ultimately, the service aims to give people a life, not just a service. The organisation builds their services upon the values of dignity, respect, empowerment, diversity and integrity.

Approximately 140 adults with autism currently receive support services from the organisation. The service is operated within a social care model and was under the leadership of a recently appointed Chief Executive Officer, a Director of Services, a Director of Finance, a Quality and Safety Department, and a Senior Management Team. The Senior Management Team have responsibility in leading their staff teams in service delivery and continual service development and expansion. The Quality and Safety Department are responsible for ensuring that the culture of quality is considered a built-in component of all aspects of service delivery, rather than a bolt on addition. The quality department are bound by national standards and regulations for day and residential

services, and internally run a host of measurements for structure, process and outcome improvements.

1.6.1.2 Model of Service

Over the years of the organisation's existence, due to the individual nature of people with autism, the model of service has been changing in an effort to best suit the needs of the individuals receiving support services. Initially, the organisation only provided services to people who would have been classified as having 'classic autism', and services were organised into day service and residential services. Until approximately 15 years ago, the day services consisted of large day centres which provided supports to approximately 25 people with autism per building.

Responding to the increased number of people being diagnosed with autism, and often Asperger's Syndrome, as well as the influences of policy documents, the organisation began to move people out of the larger day service settings and open up smaller hub-like day services in the community. The people attending these large day centres, who already had a residential placement, were mostly moved out of the day centres to receive 24-hour support from their home. The new model of day services was termed 'outreach' and the level of support provided to individuals ranged from 2 hours per week, to 30 hours per week. In addition, a new model of residential services was developed, which began to work with people in their own single occupancy homes, ranging from drop-in services to one-to-one 24-hour support.

At the time of this study, the various work site locations could be grouped into three, that is, The Garden, Residential and Outreach Residential Services, and Day Service and Outreach Day Services. Each individual work site differs in context, roles, responsibilities and working hours. In addition, the staffing models differ in all work site locations. Day service staff usually work 9am to 5pm, with outreach day service staff often working evenings and weekends. Residential staff work for a period of 24hours and may be working in a group home where there are two staff present, or lone working in a single occupancy house.

1.6.1.3 Funding

The setting involved in the research was a voluntary body with charitable status and is funded by the Health Service Executive (HSE). All referrals to the service come from a

person's HSE Disability Manager and are then handled by the relevant management structures within the service, who carry out an assessment to determine the level of support requested and required by the individual.

Clinical services consisting of psychology and occupational therapy are included in the funding package for all service users. Psychiatry and nursing services are included in the funding for residential service users only, however facing ethical dilemmas, the service has in the past provided psychiatry and nursing services to those without funding. Speech and Language Therapy services must be bought in from private companies or accessed through community services for all service users.

1.6.1.4 Social and Cultural Environment

Finally, the social and cultural environment of the disability service setting is discussed.

History of the service

In order to provide an accurate description of the history of the organisation, the researcher interviewed a senior member of the organisation who has been working in the service for the past 29 years. A brief synopsis of the history of the organisation is given in order to provide context to the current environment of the disability service setting.

In the 1960's in Ireland, children with autism were beginning to receive their diagnosis of autism and were attending special schools. The parents of these children began to worry about service options for their children after leaving the special school environment. At the time, the children who were living at home would continue to live at home with their parents after school. For the children who were in residential care, they would move to the then termed "mentally handicapped institutions" or psychiatric hospitals. The parents of these children in the late 1960's began to lobby the Health Board to develop a specific adult autism service for these children and adults with autism already in institutions and 'lunatic asylums'.

The parents succeeded in their efforts, and the organisation was founded in the early 1970s, as the first autism specific service in Ireland. The organisation was formed as a limited company with a Board of Directors, consisting of three parent representatives and three Health Board representatives. Initially, a residential house in the community was opened as a day service for adults with autism, and in the following years, residential

services began to open. At this time, the profile of the people receiving a service from the organisation were people with what was termed 'classic autism'. It was not until the 1990's that the organisation became aware of the diagnosis of Asperger's Syndrome and began to tune into the international debate regarding the diagnosis of autism. A leading member of the organisation completed Autism Studies in the UK, which influenced the perspective adopted by the service, where autism was seen as a developmental disability.

In the early years of service development within the organisation, it was accepted that the psychiatry model of service delivery was not suitable to people with autism, which was heavily influenced by the medical professions and a culture of medicating to manage behaviours. The service was influenced by principles of normalization in the 1970's, which held a perspective that people with disabilities should be offered the same opportunities and conditions of everyday life as other citizens (Wolfensberger & Tullman, 1982).

It was decided within the organisation, that the response to challenging behaviour witnessed within psychiatry at the time, was inappropriate for use with people with autism. The organisation began looking for a model for supporting challenging behaviour in people with autism, and in 1995 discovered Studio 3, who promote *"the management of challenging behaviour in a gentle and dignified way, by providing a better understanding and insight into challenging behaviour and by use of low arousal approaches and gentle physical skills"* (Studio 3 Training Systems, 2018, para. 2). The philosophy of the service began to grow out of the Low arousal approach, which *"emphasises a range of behaviour management strategies that focus on the reduction of stress, fear and frustration and seeks to prevent aggression and crisis situations"*, by striving to identify triggers and using low intensity strategies to prevent punitive consequences for people experiencing challenging behaviour (Studio 3 Training Systems, 2018, para. 2).

In addition, the service was influenced by the writings and teachings of David Pitonyak. Upon meeting David Pitonyak, members of the service were heavily influenced by his simple statement that 'challenging behaviour is the result of an unmet need'. This simple statement infiltrated the service and influenced its non-judgemental and moralistic philosophy and perspective on adults with autism. The service thereafter adopted the view that challenging behaviour was a result of the person's inability to express their basic needs and wants, and often to communicate pain. The focus was then to foster a skill in

staff where they would endeavour to meet the need being expressed by people with autism.

In recent years, the service has been heavily influenced by the regulator HIQA, which the informant of this historical report believes has largely enhanced service delivery. HIQA has helped with emphasising the importance of evidencing how staff are supporting people with autism, so that staff can provide rationale for the support provided. HIQA has been a significant contributory factor to the changes that have enhanced service delivery in the past number of years, however, the informant believes that the model HIQA have adopted is not helpful, as they send out the message that if regulations aren't abided by, 'we'll close you down'.

Cultural environment

The cultural environment of the service is largely one which accepts each person's individuality and difference. Within the various locations, given the age range of service users who access the service, there are different cultures existing. The older people with autism often maintains old routines such as celebrating public holidays and religious occasions. Often, various locations host Christmas parties where people who previously attended day service together meet up and have Christmas dinner. A number of the young adults with autism, for example within the outreach services, would attend various conventions throughout the year, such as Comic Con. These events celebrate various television shows, comics, gaming and cosplay. The staff members of the service respect each person's own cultural values and rituals.

1.7 Research Aim

The need for this study emerged from the researcher's experience of working within the autism service and observing the various support models available to people with autism. The researcher views people with autism as occupational beings, who often need support to participate and engage in valued occupations in their day to day life. The researcher was interested to investigate the factors that support or inhibit how adults with autism are supported in occupational engagement in their day to day lives.

There is a paucity of literature looking at staff's support of adults with autism in occupational engagement in disability services in Ireland. Among the literature examining

services for people with autism, most have focused on early intervention and child-based services (Gerhardt & Lainer, 2011). There is emerging literature in the area of transitioning to adulthood and adult support services (Thompson, Bolte, Falkmer, & Girdler, 2018; Havlicek, Bilaver, & Beldon, 2016; Senland & Higgins-D'Alessandro, 2016). Many studies discuss staff factors working in other contexts, such as intellectual disability services, but not directly relating to supporting the occupational engagement of adults with autism and comparisons between day, residential and garden services. Perhaps in response to this lack of research in the area, the HSE (2017) launched a national review of services provided to people with autism across the lifespan. This study will add to the body of research around the development of support services for adults with autism, with particular focus on occupational engagement.

The researcher values the perspective of the frontline staff (Kadri, et al., 2018) in how they support the occupational engagement of people with autism. Therefore, the aim of this study is to explore staff members support with adults with autism in occupational engagement in their daily lives, within the context of an Irish disability service. The objectives established to achieve this aim are as follows:

- How do staff offer support to service users in participation?
- How do staff offer support to service users in their daily routine?
- How do staff offer support to service users in communicating in their everyday life?
- How do staff offer support to service users in social contact within day to day routines, hobbies and interests?

In order to meet these objectives, semi-structured interviews were completed with staff working with service users with autism from different work site locations. Staff were categorised into one of three groupings:

- Day service staff
- Residential service staff
- Garden and maintenance staff

1.8 Description of Research Sample

The eight participants for this study were recruited using purposive sampling, to ensure the most productive sample was used to answer the research question (Mason, 2002).

The research population comprised of any staff member within the service who was working directly with a person with autism in their daily life. Staff members not working directly with people with autism were not included in the research study.

1.9 Overview of Methodology

The qualitative descriptive method of qualitative research was used to explore the research topic (Sandelowski, 2000). Semi-structured interviews were used to allow the participant the opportunity to elaborate on their unique experience of the research question (Taylor & Francis, 2013). Thematic analysis was used to analyse the data (Braun & Clarke, 2006).

1.10 Researcher's Professional Background and Assumptions

The researchers experience prior to the beginning of this research study was fundamental to the formation of the research idea. The researcher began working in the organisation involved in this study immediately after finishing her undergraduate degree in occupational therapy. The researcher began working in the outreach day services with young adults with autism, in the role of care assistant. Having come to the service straight after college, the researcher had an occupational perspective of the world and brought this to the day to day work. After a number of weeks in the post, the researcher realised that not all staff on the team held the same perspective. The researcher felt that staff were not working from a support reduction model, which did not leave space for advocacy, voice or choice.

The researcher spent just 6 months working with this team and requested a move to another team within the outreach day services which worked with people with Asperger's Syndrome. The researcher again was struck by the perspective of the staff team, whom were not working from an occupational perspective. While working with both teams, the researcher began a culture change process, where she attempted to influence the thinking of the staff team, incorporating concepts such as occupation, responsibility, advocacy, voice and choice.

Support staff were initially resistant to the researchers' differing views, but slowly the teams began to adopt the occupational perspective and began advocating for increased choice and autonomy for the person. This insight gained from working alongside support

staff was invaluable to the researcher's professional development and motivation to carry out research in the area. The researcher gained an understanding of social care, the perspective adopted by social care staff and, ultimately, how to influence this perspective to include occupation. The researcher believes this culture change was possible and successful due to the consistent presence of the researcher working on the same level as the support staff, where not having the status as clinical staff seemed to be an advantage. Everyone's view counted equally. In addition to the researcher's position among the teams, management were receptive of change and supportive of staff experimenting with new ideas and perspectives.

The researcher availed of mentoring throughout this period of culture change working on the two teams, which was a vital part of her ongoing professional and clinical development (Christie, 1999). In addition, the organisation was very receptive of the occupational lens offered by the researcher. The service requested the researcher to take on more responsibility and work in other areas of the service, and subsequently offered the researcher a post as occupational therapist. The researcher then left the staff team and joined the clinical team, where there was now an expectation for assessment and intervention and a need to arrange meetings with support staff across the service, putting the researcher in the shoes of a professional.

During the early period of the post, the researcher spent most of her time working in one particular residential house, with the aim of bringing the occupational perspective and supporting staff members to support the person's occupational engagement and participation. The researcher was struck by the different environment, different people with autism and perspectives held by the staff in comparison to the day service model. As an occupational therapist, the researcher began to work across all locations within the service, meeting support staff, all with different backgrounds and working within different environments, such as the garden, residential and day services.

This experience as a whole, has shaped the researcher's clinical approach, adopting a focus on occupational engagement and a curiosity of the environment of the disability service, and how this might impact the staff's approach and the person's experience of the support and choices available to them. The researcher opposes the medical model view of people with autism and aligns herself with an affirmative model of disability (Swain & French, 2000), where people are affirmed to be okay with who they are, and

that they may require support to engage, but how as occupational therapists and support staff can we support them to live a fulfilling life of their own choosing?

The use of a reflective diary and the researcher bias is reported on in the methodology chapter.

1.11 Limitations of Study

The main limitation of the study was that it only explored support staff's views on supporting the occupational engagement of adults with autism in their daily lives. The views of people with autism themselves were not explored, which goes against McKinnon's (2000) advice to involve clients in research as a means to ensure services remain meaningful to the person. In addition, the views of the management within the service were not sought.

The limitations of the study are further discussed in the Discussion chapter (Section 5) and recommendations for future research are presented.

1.12 Definition of Terms

Occupational engagement – involves engagement in all kinds of everyday activities and relates to the degree to which a person; experiences a sense of meaning from occupation, has a variety of occupations that create a daily rhythm, initiates occupations, interacts with other people and acts independently (Tjornstrand, Bejerholm, & Eklund, 2015). Engagement is less concerned with the actual performance of the occupation but also the level of importance and satisfaction it brings to the person (Townsend & Polatajko, 2007).

Participation – refers to “what the person can do, wants to do, has the opportunity to do and is not prevented from doing” (Mallinson & Hammell, 2010, pp. S29-S33).

Participation involves engagement in meaningful activities that is sustained by a person's capabilities within the context of their environments. For the purposes of this study, engagement and participation are taken to mean the same thing.

Health Information and Quality Authority (HIQA) – HIQA was established as an independent authority to ensure health and social care services delivery high quality and safe care to people using services in Ireland. The authority's role is to develop standards,

inspect and review health and social care services and to support informed decisions on how services are delivered, all grounded in a value system that puts service users at the centre of their work (HIQA, 2007).

Person with autism – person with a diagnosis of autism spectrum disorder, or otherwise classified under previous editions of the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013). The term ‘person with autism’ is used interchangeably with ‘autistic person’, throughout the study.

Service user – For the purposes of this study, a service user is defined as a person who receives any kind of support services from a disability service.

Support staff – For the purposes of this study, a support staff encompasses all staff working with a person with autism, incorporating staff with differing backgrounds and qualifications.

Residential Service – Referred to in other countries as ‘group homes’, typically taking the form of a house in a residential area, where support is provided to people in a house-share arrangement, in the community or on-site of a campus-style setting (HIQA, 2017). The outreach residential service relates to the supported or assisted-living model (HIQA, 2017), where people are supported to live on their own, with level of support from staff depending on the needs of the person.

Day Services – For the purposes of this study, day services encompass new and old models of day services provided to people with disabilities. The older model of day services was organised as segregated services, separate from the community, with limited activity options, experiences and choices available to service users (HSE, 2012). The New Directions (2012) policy defines the new direction for day service supports as tailored to individual need, flexible, responsive and person-centred. The person may receive these supports in their own home, in the community, or in the building of the service.

1.13 Abbreviations Used

ASD – Autism Spectrum Disorder

CMOP-E – Canadian Model of Occupational Performance and Engagement

DSM: – Diagnostic and Statistical Manual of Mental Disorders

HSE – Health Service Executive

HIQA – Health Information and Quality Authority

ID – Intellectual disability

1.14 Conclusion

This chapter has introduced the theoretical foundations of the study, the context and background of the study, exploring why the research topic was completed. The following chapters detail a literature review, followed by a description of the methodology used, results and discussion chapters.

Chapter Two – Literature Review

2 Literature Review

The main focus of the literature search was on factors affecting social care staff supporting adults with autism in their daily lives. The researcher used the following databases: Academic Search Complete, CINHAL, PubMed and Psych Info, as well as a variety of related literature, policy documents and books. The researcher used the following search terms, 'person-centred care', 'adults with autism', 'social care', 'leadership', and 'culture', all relating to the disability service context in which adults with autism are supported.

Table 3: Literature search strategy

Databases used	Search terms	Number of studies found	Exclusion criteria
Academic Search Complete; CINHAL; PubMed; and Psych Info	'Person-centred care'; 'adults with autism'; 'social care'; 'leadership'; 'disability service'; and 'culture'.	A total of approximately 1,200 articles were identified using the stated search terms. 344 of these were chosen as relevant and reviewed as part of background reading. Approximately half form the basis of this literature review.	1. Studies relating to the support of children with autism 2. Studies relating to the diagnoses and cause of autism spectrum disorder

The introduction chapter presented the concept of occupational justice and the Canadian Model of Occupational Performance and Engagement, and relationships between staff and people with autism. The following literature review is separated into three parts. Firstly, a detailed description of person-centred care is offered within the context of supporting the occupational engagement of adults with autism in their daily lives.

Part two of the review presents an analysis of the guiding policy documents that influence service provision in autism specific services in Ireland. Part three examines the literature

on the workings of an organisation, at the level of individual staff member, staff teams, management and leadership, and how these factors may influence quality of life as experienced by the person with autism.

Part One

2.1 Person-Centred Care

Person-centred care has been discussed largely in the literature around Dementia and care of the older person. The occupational therapy profession, for over thirty years has been proclaiming an allegiance to client-centred practice (Whalley Hammell, 2013), with the World Federation of Occupational Therapists (WFOT) (2010, p. 1) declaring that *“occupational therapy is client-centred”* and that *“occupational therapists are person-centred in their relationships with clients”*. The concept is also advocated for in relation to supporting children and adults with autism to have a good quality of life and to reach their full potential (Beadle-Brown, Roberts, & Mills, 2009).

2.1.1 Definitions and Origins of Person-Centred Care

Person-centred care is considered the gold standard in providing services and supports to those who need it. The person-centred operational system, which focuses on people's holistic well-being and maintenance of their humanity, has replaced the paternalistic, hierarchical operational systems of the past, where ‘professionals know best’ and decision makers are distant from service users (Love & Kelly, 2011). The central concept of person-centred care, personhood, is a *“standing or status that is bestowed upon one human being by others, in the context of relationships and social being. It implies recognition, respect and trust”* (Kitwood, 1997, p. 8).

The precise origins of person-centred care are not clear, but many credit a Nobel Peace Prize Nominee of the mid-20th Century, the American psychologist and founder of the humanistic approach to psychology, Carl Rogers (Love & Kelly, 2011). In the 1970s, the Disability Movement developed to campaign for the rights of people with disabilities to be recognised and for society to better accommodate people with disabilities (Oliver, 1990). Out of this movement, emerged another person-centeredness pioneer Tom Kitwood, who began using and applying the concept of ‘personhood’ to people with dementia in the 1980s (Mitchell & Agnelli, 2015). His psycho-social person-centred model of care aimed to maintain the intrinsic personhood of each person receiving care (Kitwood, 1997).

Person-centred care ensures services and supports are built on values that promote relationships and honour people's right to respect, privacy, self-determination and

individuality (Love & Kelly, 2011), therefore challenging the reductionist perspective of the medical model and promoting concepts of well-being, quality of life and participation (Cole & Tufano, 2008). Rogers emphasized that the best way to come to understand a person was to use their own “self-view” (Cole & Tufano, 2008, p. 26), that is to recognise their unique perspective of the world.

2.1.2 Core Concepts of Person-Centred Care

The person-centred approach is held by some to be a ‘philosophy’ and ‘set of values’ which include ‘really respecting the dignity, autonomy and capacity for change of people’ and a belief that ‘people move in the direction of self-actualization’ if a ‘growth-promoting atmosphere’ is offered (Wood, 2008, p. 13). Kitwood (1997) stated that a person-centred approach requires empathic care and support to meet a person’s six psychological needs: love; attachment; comfort; identity; occupation; and inclusion. Rogers stressed that the success of a therapeutic relationship relies heavily on the therapist’s ability to show genuineness, acceptance and empathy, coupled with the person’s ability to perceive these expressions (Cole & Tufano, 2008). Person-centred care is this therapeutic relationship aimed at meeting a person’s six psychological needs (Kitwood, 1997).

2.1.3 Person-Centred Care in Practice

Traditionally, people with disabilities have been expected to fit into services, with little input into the design or delivery of the service they receive (Dowling, Manthorpe, & Cowley, 2006), often being thought of as passive recipients of care (Rose, 2003). Stainton (2002) has claimed that the ‘needs’ of people with disabilities have been determined without reference to the individual in the belief that disability related needs are universally rather than individually defined. This history does not fit with a person-centred approach.

It is important to note that residential services for people with disabilities and those for older persons are both regulated by the same body, HIQA (2013). O’Dwyer (2013) found that residential services for older adults in Ireland is underpinned by a consumer-driven model of person-centred care, meaning that residential care is portrayed as a hotel-like service and residents as discerning customers, with an emphasis on resident ‘choice’. However, O’Dwyer argues that perhaps this model of person-centred care is not suitable

to a population that may largely have limited capacity to make key choices and that it may be irrelevant to the fulfilment of a person's needs and may even inhibit their well-being as they are being asked to take greater responsibility over their own care. Within O'Dwyers (2013) study, the development of the HIQA standards for residential care of the older person in Ireland was discussed, and interviews were completed with previous members of the Working Group tasked with drawing up the standards. Interestingly, O'Dwyer (2013) found that the majority of the working group members were largely removed from the day-to-day practice of supporting older adults in residential care, which had an impact on their conceptualisation of person-centred care. They had difficulty defining the term as they were not familiar with the literature on person-centred care and simply relied on their own subjective viewpoints to decide what should be written in the Standards. The researcher questions then, if a similar study was undertaken on the development of the HIQA Standards developed for Disability services, what might be revealed?

The Standards for residential services for adults with disabilities state that *"a person-centred approach to service provision is one where services are planned and delivered with the active involvement and participation of people who use services"*. In the descriptions of 'individualised supports and care' there is a heavy emphasis on people *"exercising their rights"*, making *"informed decisions"*, *"choices"* and *"wishes"* (HIQA, 2013, p. 63). The researcher questions, what then is the meaning of 'person-centred' if a person's decision-making abilities are compromised, or if the process of decision-making and choices is much more complicated than normal?

Within social care, person-centred planning is used as a way of organising human services, so that they are person-centred (Mansell & Beadle-Brown, 2004a). Person-centred planning is grounded in learning through shared action, finding creative solutions to problems rather than fitting individuals into boxes and working together over time to create positive change in the person's life, in communities and in organisations (Sanderson, 2000). Every person with autism is different, and so, a one size fits all approach is unsuitable (Koenig & Kinnealey, 2010). There is support in the literature of the importance of targeting the specific needs of adults with autism to ensure autism specific, tailored service provision (Herrema, et al., 2017; Bennett, Wood, & Hare, 2005).

In 2006, Dowling, Manthorpe and Cowley conducted a review of person-centred planning in social care in the United Kingdom, in order to investigate the barriers and bridges to

implementing person-centred care in practice. They reported that within social care there had been a shift towards person-centred care and person-centred planning, however, despite this being widely endorsed, it had yet to be fully adopted and implemented in practice. Despite the policy focus on person-centred planning and the common knowledge that it is the way forward for service provision, they concluded that it had proved easier to talk about than actually do (Dowling, Manthorpe, & Cowley, 2006).

Person-centred planning has strong foundations in a rights-based approach, acknowledging and advocating for the rights of people with disabilities, as set out by the United Nations Convention on the Rights of Persons with a Disability (United Nations, 2006). In Australia, in order to facilitate this, person-centred approaches were accompanied by the introduction of individualised funding (Broady, 2014), a fundamental mechanism in establishing person-centred systems (O'Brien, 2001). Under this system, funding is not directly assigned to services, but rather to the individual, who can then choose which services they avail of and from whom (Lord & Hutchison, 2003).

Within the Irish context, there is a community of learning facilitating the movement towards more individualised supports for people with intellectual and developmental disabilities, the Next Steps Project. The project and its values are in line with current Irish disability policies, with a vision for 'individualised supports for an ordinary life'. The community is working with people themselves, their families and service providers to support people to achieve greater independence and full active citizenship, with results such as: people moving out of congregated living; people having more connections with family and friends; community participation; people going on holidays and reported increases in general confidence and independence (Harnett, 2013).

For people with severe and profound intellectual and developmental disabilities, person-centred active support is a way for people to provide enough support to enable people to make the most of available opportunities at home, in their community and in their relationships, and has been shown to increase engagement in meaningful activities and relationships (Beadle-Brown, Hutchinson, & Whelton, 2012; Stancliffe, Harman, Toogood, & McVilly, 2007). Stancliffe et al (2007) analysed the effects of active support upon 20 residents with intellectual disabilities and 2 with acquired brain injuries, living in five group homes in suburban Sydney, Australia. All staff working in the group homes were trained in Active Support, and participated in a pre-test – post-test design, without a

control group. The research team used observational and written assessments tools, similar measures to that of Beadle-Brown, Hutchinson & Whelton (2012), a UK study with a similar sample size of 33. Although both studies used inter-observer reliability measures within their methodology, results should be interpreted with caution, due to their small sample size, lack of a control group and lack of data on long term maintenance of the effects of Active Support.

The basis of this approach is the enabling and empowering relationship between those providing support and those being supported. The approach requires staff to slow down, to remove the focus from paperwork and recording what was done, to focusing on the experience of the person being supported. The four key principles of the approach are, every moment has potential; little and often; graded assistance to ensure success; and maximising choice and control (Beadle-Brown & Hutchinson, 2016).

Maslow (2012) focused much of his work on the nature of the self-actualizing person and is well known for establishing the theory of hierarchy of needs, which states that a person is internally and externally driven to satisfy their needs and to reach a sense of fulfilment. Maslow's concept of self-actualization closely relates to the matters of well-being and quality of life largely mentioned within occupational therapy literature and the CMOP-E model (Cole & Tufano, 2008).

2.1.4 Person-Centred Care and Occupational Therapy

The literature suggests that early occupational therapists valued patient or client perspectives and regarded such as a core element of their practice, emphasising a variety of interventions directed to either the person or the occupation (Rebeiro, 2000). However, despite this early appreciation of the client and their interests, the profession's focus shifted in the mid-20th century to a more condition and symptom-based view of the individual (Cole & Tufano, 2008). This alliance with medicine resulted in a focus on impairment and the abandonment of foundational occupational therapy principles (Mosey, 1971). This shift in focus effectively removed the person from the decision-making process and positioned them under the control of knowledge and authority of the 'professional'. This chiasm distanced occupational therapy from understanding the meaning and purpose of therapeutic occupation for people with disabilities (Rebeiro, 2000).

In the 1960s and 1970s, Mary Reilly and others began to call for a realignment to the profession's original mission and a renewed focus on occupation (Kielhofner & Burke, 1977). At the same time, health care was becoming increasingly self-defined and as more than the reduction of illness, calling on professions to define which health need they fulfilled within society. A shift from a focus on illness to one which was concerned with health and well-being began, a re-focusing on the person as central to clinical practice (Rebeiro, 2000).

In 1995, Law, Baptiste, and Mills defined client-centred care as an approach to care *"which embraces a philosophy of respect for, and a partnership with, people receiving services"* (p.253). They outlined seven key concepts of client-centeredness, including: autonomy/choice; responsibility; partnership; enablement; accessibility; contextual congruence, and respect for diversity. Although this was and is recognised and valued within the profession, it is well acknowledged within the literature that challenges exist in realising true client-centeredness in real day to day practice (Rebeiro, 2000). The challenge of placing the person at the centre of practice, involving them in decision making and offering opportunities as opposed to prescriptive activity, is acknowledged and speaks to the need for occupational therapists to move away from the medical model and towards a context of health promotion and wellness (Rebeiro, 2000).

Challenges to implementing person-centred practice exist at three different levels: the level of the system, the therapist and the person (Wilkins, Pollock, Rochon, & Law, 2001). At the level of the system, there can be challenges in gaining commitment from staff, developing strategies for change, living the philosophy, giving time and resources to allow change and with service structures and policies that may hinder change. At the level of the therapist, challenges present relating to the therapist's understanding of person-centred care, a reluctance to change old habits and routines of practice and making the shift of power to partnership in the person-therapist relationship. At the level of the person, challenges relate to the person's ability to engage in a collaborative relationship and when shifting the power imbalances of the relationship (Wilkins, Pollock, Rochon, & Law, 2001).

Sumsion (2006) presents similar challenges that the occupational therapist may face when attempting to implement person-centred practice, which are therapist barriers, client

barriers and barriers presented by the work environment. Therapist barriers can include factors such as risk management, safety and the therapist's confidence. Client barriers can include family contexts, cultural differences, educational background and problem-solving skills. Barriers presented by the work environment are issues such as time and team work of the multi-disciplinary team (Sumsion, 2006). In order for person-centred care to be implemented with success, a whole team effort and commitment is required, with each staff member having a key role in instilling the approach within the organisation (HIQA, 2013). Each member of the organisation must work collaboratively together to address change at each of the levels mentioned above, ultimately ensuring each person receives a service that is respectful, supportive, individualised and coordinated (Wilkins, Pollock, Rochon, & Law, 2001).

Participants in a study completed by Corring and Cook (1999) suggested that service providers wishing to practice in a client-centred fashion need to value and appreciate the life experience of their clients and recognize their expert knowledge of themselves. This study demands occupational therapists not to lose sight of the human being affected by illness or disease, just as Williams (1992) does with regard to people with autism. Participants in Rebeiro's (2000) study offered insight into where occupational therapists are going wrong with person-centred care, describing activity prescription, no choice and a focus on condition rather than the person. The participants recommended focusing on occupational choice, the person rather than the condition and providing a supportive and an accepting environment as ways to best adopt a person-centred approach (Rebeiro, 2000).

Koenig and Kinnealey (2010) provide occupational therapists with a model in order to combat this 'one size fits all' culture in their work with people with autism. The Inside Out model was developed through verbal and written interviews with people with autism in order to facilitate person-centred support. At the centre of the model is the voice of the person, encouraging the reader to get to know the individual, their interests and their goals. The model instructs therapists to 'partner' the person with autism, to look past their behaviours, to presume intellect and to adapt the environment to support their engagement.

Perhaps client-centred practice can be the vehicle by which occupational therapy can grow and enabling occupation can become a reality (Rebeiro, 2000). O'Mahony and

Pettigrew (2015) put forward the view of the pioneering Irish occupational therapist, Anne Beckett, that we should remove the unnecessary dividing lines between therapists and clients.

Part Two

2.2 Guiding Policy Frameworks and Standards in an Irish Context

When discussing the services adults with autism receive in Ireland, it is helpful to take a life course perspective, acknowledging the events and society of the past, where parents were held responsible and individuals with autism faced sustained social exclusion. This affords us an appreciation of the present and helps to illuminate the way forward for practitioners, people with autism (D'Astous, Manthorpe, Lowton, & Glaser, 2016) and policy and standards. These documents influence the institutional and cultural environments of disability services, impacting their practices, values, ethos and mission statements.

Irish society is in a period of change in relation to supporting citizens with autism. Currently, there are no existing policy documents specifically relating to adults with autism receiving supports from services in Ireland. In relation to people with autism receiving residential services, HIQA provide a set of national standards for children and adults with disabilities, which adults with autism fall under. HIQA (2016) also provide policy documents for older adults living in residential care, however the unique needs of young and old adults with autism are not recognised in policy documents in Ireland.

Since 1990, a raft of policies has been developed in order to transform services provided to people with disabilities, such as the traditional congregated model of care, towards a community-based model whereby people are supported to live a life of their choosing (Linehan, et al., 2014). A Strategy for Equality; the Report on the Commission on the Status of People with Disabilities (1996) was instrumental in changing the course of services in Ireland, by proposing a rights-based approach to disability. The Commission completed a pioneering consultation with people with disabilities and their caregivers, concluding that *“people with disabilities are the neglected citizens of Ireland”* (p.4), and recommended wide ranging changes in the areas of education, health, housing, transport, research and work (Commission on the Status of People with Disabilities, 1996). Although people with autism are not specifically mentioned in the report, the scope of the report included all people with disabilities in Ireland. Years later, in 2011, the HSE published a report entitled *“Time to Move on From Congregated Settings – A Strategy for Community Inclusion* (HSE, 2011), outlining how services should proceed with moving 4,000+ people with disabilities from congregated settings into smaller houses within the community.

This policy is influencing the lives of people with autism, such as one example given with the report itself, where Kate was supported to move out of institutional care and *“have avenues of proper living opened up for her and experience unimagined opportunities”* (p.89).

In July 2017, the Autism Spectrum Disorder Bill 2017 passed through to the Fifth Stage of Seanad Éireann (Houses of the Oireachtas, 2018). The Bill will establish a national strategy for autism, which will acknowledge the challenges and opportunities facing the Irish autistic community (AsIAM, 2017). This is a welcome development, as currently in Ireland, there is neither a strategy for supporting people with autism, nor sufficient data relating to autism across the country (AsIAM, 2017).

In Ireland today, Adam Harris, founder and Chief Executive Officer of the registered charity AsIAM, is constantly educating the public and campaigning and advocating for the autism community. AsIAM (2018) have a website which provides the public with a portal of information about autism, a space for people with autism to share their own stories, and to provide a strong voice for the concerns of the community. The AsIAM Team, of both staff and volunteers, actively engage in public events all over the country, including running Secondary School Workshops in the hope of making school easier for autistic teenagers and to raise awareness of autism among young people in general (AsIAM, 2018). AsIAM (2018) have also set up a Youth Leadership Team, comprised of young people with autism who act as ambassadors for the charity, by directing and influencing the charity’s work, the media and the general public.

The central goal of the Irish Government’s reform programme for disability services, is for people with disabilities to be supported to live independent lives in the community and to make their own choices and decisions. The chosen mechanism being Personalised Budgets, an approach that has been criticised by Slasberg and Beresford (2016) in the UK, for its surface level definition of personal budgets and its inequity of use, primarily by organisations and councils with a particular interest in the strategy. However, in July, 2018, the Task Force on Personalised Budgets have published its report, which makes specific reference to people with autism and makes recommendations for the assessment process, the infrastructure and supports required for personalised budgets, the governance process and the actions to be taken by Government (Department of Health,

2018). The disability service context remains in a period of change for people with autism, but perhaps in a period of opportunity too.

2.2.1 Health Information and Quality Authority (HIQA)

In Ireland, HIQA is an independent authority established to ensure high-quality and safe care for people using Ireland's health and social care services, receiving its mandate under the Health Act, 2007. HIQA's role is to develop standards, inspect and review health and social care services, and to support decision making on how services are delivered (HIQA, 2013).

HIQA's Disability Team is legally responsible for the monitoring, inspection and registration of all residential services for adults with a disability in Ireland. HIQA want to know that adults with disabilities who are receiving residential services are safe; their rights are respected; they are included in decisions about their care; the care provided matches their personal health and social needs; and that they have a good quality of life. HIQA carry out inspections within the organisation and if satisfactory, provide registration status, valid for a maximum of three years, before the cycle of reregistration begins. Within this three-year time frame, HIQA may return to the organisation to perform monitoring or unannounced inspections to ensure the maintenance of registration standards (HIQA, 2013).

A number of issues with the regulation of social care services have been discussed in a report published by HIQA in 2017, entitled "Exploring the regulation of health and social care services". The first of these issues is the definition of a 'designated centre', which is unclear and open to interpretation, stating that it is a place where a dependant person receives care and accommodation. The report explores the different models of service provided to people with disabilities and whether they should be defined as a designated centre and therefore come under regulation (HIQA, 2017).

Participants involved in giving feedback to the review stated that the current regulations are not best suited to the residential service model currently providing services to people with disabilities, with certain elements of the regulations in conflict with the idea that the house is the person's home. In addition, the discussion groups criticised the 'one size fits all' approach within the regulations and that the regulations could come in conflict with

the Assisted Decision Making (Capacity) Act 2015 (HIQA, 2017). Participants in the discussion groups advocated for a move to a service-based approach to regulation, so that the service provider is registered rather than the physical location where the person lives (HIQA, 2017).

2.2.2 “New Directions” (HSE, 2015)

The registration and regulation of day services is just beginning to happen in Ireland. While examples of individualized supports do exist, people availing of services are still limited to a range of centre-based group activities with limited individual choice (Fleming, McGilowat, & Barry, 2017). In 2012, a proposed new approach to adult day services was introduced and was titled New Directions. The report was prompted by the way in which HSE-funded adult day services were organised in Ireland for many years, as segregated services, separate from local communities and offering limited options, experiences and choices. This review of day services proposed an approach that is grounded on the principles of person-centeredness, community inclusion, active citizenship and high-quality service provision. It highlights that people with disabilities have voiced that they want to enjoy the normal every day; having choices, doing interesting and useful things, learning skills, meeting people and enjoying their company (HSE, 2012).

Today in Ireland, there are approximately 20,000 adults with disabilities involved with day services, in which there is currently no regulation or standards (Inclusion Ireland, 2016), as there are for residential services. The “Value for Money and Policy Review of Disability Services” (Department of Health, 2012) proposes a fundamental change in approach to governance, funding and focus of the Disability Services Programme, with a move away from group-based service delivery towards a model of person-centred and individually chosen supports (Department of Health, 2012). This review provides the context of future service development, advocating that supports embed the person in their natural circle of support and wider community, availing of both mainstream and disability services. It is within this context that the Interim Standards for New Directions were developed (HSE, 2015).

In the development of the New Directions policy for day services, 1,500 people took part in a consultation process which highlighted striking differences in people’s experiences of day services, emphasizing the need for quality assurance systems and supports for

services to help them achieve common standards. Alongside stories of good experiences and worthwhile activities, the absence of choice and time spent in meaningless activities was a common theme in the consultation (HSE, 2012). The Interim Standards for New Directions aim to be a catalyst for social inclusion and self-determination in the lives of people with disabilities and to provide a framework for services to deliver on the vision and stated objectives of New Directions and the Value for Money reports (HSE, 2015). This highlights a shift from the dominant medical model of disability to an affirmative one, which encompasses positive social identities for disabled people grounded in the benefits of lifestyle and life experience of being disabled (Swain & French, 2000). As services for people with autism have been dominated by the medical model of disability since the 1940s (D'Astous, Manthorpe, Lowton, & Glaser, 2016) this policy document is a welcome support of the need for change in societal attitudes and prejudices towards those with autism.

2.2.3 Health Service Executive Autism Review

In 2012, the HSE launched a national review of services provided to people with autism. A review group was established by the National Disability Steering Group in order to identify a number of core principles for the delivery of health services to persons in Ireland with a diagnosis of ASD. The report adopts the principles of person-centeredness, equity and quality to ensure service delivery that is responsive to need, integrated, co-ordinated and seamless (HSE, 2012, p. 55).

In 2017, the Minister for Health again called for a review of the level of supports and services being offered to people with ASD. The first term of reference listed is to review the National Review that took place in 2012, which had some very similar terms of reference to that released in 2017. A cross divisional working group was established to consider the operational effectiveness of health services responses in addressing the particular needs of those with ASD and to identify models of good practice (HSE, 2017). The working group held consultations in the form of workshops with service providers, service users, family members and professionals in 2017. Despite the HSE's statement that the review would be published in September 2017, it had not been released at the time of submission of this thesis.

2.2.4 National Program to Enable Cultures of Person-Centredness

Currently within the HSE, there is a national programme ongoing to enable cultures of person-centredness within health and social care services in Ireland (HSE Quality Improvement Division, 2017). The group are working to implement a framework of person-centred practice to improve the delivery of quality care, practice and outcomes within organisations. This is achieved by appointing work-based facilitators who can lead culture change that supports person-centred practice within their own organisations. The program is based on McCormack and McCance's (2016) person-centred practice framework and more broadly on Schein's (1990) model of organisational culture; Plesk and Wilson's (2001) understanding of patterns, behaviours and culture; and Gaffney's (2011) concept of Human Flourishing.

Of interest to the current discussion is that the national programme is based on Gaffney's (2011) concepts of human flourishing, applying them specifically to the human flourishing of staff within organisations. Gaffney (2011) asserts that the experience of flourishing is when a person reaches their best self, their true spirit, where they feel alive because they believe they are doing what they were put into the world to do. This is relevant to social care staff, as a central motivation of health and care workers has been found to be an altruistic orientation (Miers, Rickaby, & Pollard, 2007), where many begin their working lives with a special desire to help others. Gaffney (2011) describes four essential elements of flourishing, which are presented below:

- Challenge: a demand for the person to do something, to get past an obstacle, to participate with a life task, to make something happen.
- Connectivity: being attuned to what is happening within oneself and outside oneself.
- Autonomy: to have the freedom to move and to pursue a challenge. Autonomy gives the person the energy to begin working towards a goal.
- Using your valued competencies: the experience of using your talents to the fullest, especially those that are most meaningful to the person.

Part Three – The Organisation

The final part of the literature review presents a discussion on the inner workings of disability services, with reference to their history in Ireland and the development of a new professional, the social care worker. The impact of the work on staff is discussed, alongside the management and leadership of disability services.

2.3 History of Disability Organisations

Autism existed long before it's label, long before there were charities and organisations for it and long before there were books and films about it (Williams, 1996). However, it is a recently recognised disorder, first identified in 1943 by American psychiatrist Leo Kanner, with the first cohort of children diagnosed with autism, now in their later years (D'Astous, Manthorpe, Lowton, & Glaser, 2016). The medical model of disability conceptualised autism as an individual problem, where impairments and differences were to be treated or fixed by medical professionals. Early clinicians and researchers believed autism was linked to schizophrenia (Silverman, 2011) and until the mid-1960s it was undifferentiated from mental retardation or mental illness. Often, the best 'solution' for the person recommended to families at the time, was institutionalisation (Bettelheim, 1967).

Unlike many European states, Ireland was very slow in providing separate and specialised provision for people with intellectual disabilities or 'mental defectives' as they were then called, with only one such hospital in existence in 1900, Stewarts Institution (Linehan, et al., 2014). From this time on, the Irish state adopted a hands-off approach (Comptroller and Auditor General Report on Value for Money Examination, 2005) and the Irish disability sector landscape was dominated by large institutions run by religious organisations (Fleming, McGillowat, & Barry, 2017). In 1958, the first classificatory count of people within mental institutions in Ireland took place, showing that 11% of hospital residents were there primarily because of an intellectual disability, and 50% of residents were classified as schizophrenic (Walsh & Daly, 2004).

In the period from the 1970s to the 1990s, scientific and medical understanding of autism expanded, increasing public awareness and new directives in social care services (D'Astous, Manthorpe, Lowton, & Glaser, 2016). In 1984, a landmark Green Paper on Services for Disabled People was published that was seen as a start for more inclusive

policies in Ireland to promote community integration of housing and services (Fleming, McGillowat, & Barry, 2017), along with the move towards a rights-based approach as a result of the report, 'A Strategy for Equality' (Commission on the Status of People with Disabilities, 1996), as discussed in the introduction chapter. A number of policy documents based on international best practice have since been developed, with the more recent 'Value for Money and Policy Review of Disability Services in Ireland' (Department of Health, 2012). This policy is used as the benchmark for achieving improvements in the disability sector, recommending the provision of 'supports' rather than 'services' in supporting the transition from a largely institutionalized to a personalized model of service (Fleming, McGillowat, & Barry, 2017).

Social care has a long history in Ireland and for many years was left in the hands of charitable and religious organisations with state oversight fragmented and inconsistent (Fanning & Rush, 2006). During the 1970s, 1980s and 1990s several cases of child neglect and abuse drew public attention to the social care sector and reports written following these cases, largely contributed to shaping social care as we know it today (Lalor & Share, 2013). Through the voices and actions of individuals advocating for change, along with improved knowledge, the social environment and services for individuals with autism is very different today, to that of seventy years ago. However, despite improvements in children's services and social inclusion, social care services and support for adults with autism remain inadequate (Cadman, et al., 2012).

2.4 The Irish Social Care Worker

In Ireland, a new professional, the social care worker, has been established and statutory registration and regulation of the new profession is an impending reality (CORU, 2017). However, the new profession itself has yet to be clearly defined. Lalor and Share (2013) discuss this difficulty with a definition of social care and state that for many years its suited governments and agencies not to have a clear definition, as it helped keep salary scales and career structures vague. The Irish Association of Social Care Educators defines social care as *'a profession committed to the planning and delivery of quality care and other support services for individuals and groups with identified needs'* (as cited in Lalor & Share, 2013, p. 4). It has been held that this definition is sketchy and could be applied to many other helping professions (Lalor & Share, 2013).

A second definition of social care emerged, which was expanded to include a description of roles, values and formation of professionals in the field. It describes specific client groups that social care workers “*support, protect, guide and advocate*” for, and describes skills that professionals require, such as empathy, self-awareness, communication, team work and critical reflection (Social Care Association of Ireland CLG, n.d.). Social Care Ireland (n.d., p. Para 1) add that social care is “*based on interpersonal relationships which require empathy, strong communication skills, self-awareness and an ability to use critical reflection*”. Lalor and Share (2013) conclude that the reality of social care practice is that it does not always adhere closely to any definition.

The Health and Social Care Professionals Act in 2005 put in place structures for the statutory regulation of ten professions, including social care work. The Health and Social Care Professionals Council (CORU) was established in 2007 as the overseeing body of the registration and regulation of the profession. It has been argued that one of the outcomes of the 2005 Act was a sudden shift in status and expectation for social care staff, from ‘worker’ to ‘professional’. This shift had particular implications for staff working in organisations without qualifications, as they were then termed ‘unqualified’ staff. This problematic term appeared to weaken the broad experience and varying skill sets such employees had often developed over years of working with people in services. Under this new legislation, it will be required for all current and future social care workers to register to practice as a professional social care worker (Finnerty, 2012).

It is important then, to consider staff’s professional identity in the changing climate of social care practice. Professional identity has been widely defined, with Adams, Hean, Sturgis, & Macleod Clark (2006) describing it as *‘the attitudes, values, knowledge, beliefs and skills that are shared with others within a professional group and relate to the professional role being undertaken by the individual, and thus is a matter of the subjective self-conceptualisation associated with the work role adopted’* (p56). Briggs (2007) also describes professional identity in terms of values but adds that they must be consciously professed and reflected on over the professional lifespan. Finnerty (2012), when examining professional identity and the Irish social care worker concluded that participants repeatedly emphasised a values-based approach to their work that held the individual at the centre. The participants alignment to Evan’s (2008) emphasis on trust, value and power in the professional-client relationship, and to Hoyle’s (2001) focus on quality of service, lead Finnerty (2012) to the conclusion that the approach of ‘new

professionalism' has particular significance when considering professional identity and the Irish social care worker.

The concept of 'new professionalism' has much to offer social care, with its emphasis on the professional-client relationship and matters such as trust, values and power (Finnerty, 2012). The relationship is considered fundamental to professional effectiveness in care settings (Peternelj-Taylor & Yonge, 2003) and in services for people with disabilities, as it is through relationship that the important work with service users is accomplished (Eraut, 1994). Indeed, the core concepts of 'new professionalism' fit with those of the occupational therapy profession and person-centred care.

An important aspect of professionalism, is that of employee engagement. Finnerty (2012) found high levels of employee engagement among social care participants and linked this to the need to develop relationships at an interpersonal level, concluding that participants were highly emotionally engaged in their work. Finnerty (2012) identified four components of engagement that have particular relevance to social care work and the development of professional identity: the positive outcomes of high employee engagement; a focus on self in the work role; connection to others; and meaningfulness in work. Kleunen & Wilner (2000) advise that frontline workers be involved in decision making regarding the person's care plan to enhance employee engagement. Gaffney (2011) too provides four elements of human flourishing that may impact on employee engagement: the need to be challenged; to feel connected; to have a level of autonomy; to use your valued competencies. When all four elements work together, they build the upward positive spiral of human flourishing (Gaffney, 2011).

Due to the close professional-client relationship that arises in social care, it is imperative that staff are supported to manage their feelings (Finnerty, 2012).

2.4.1 The Management of Feelings - Emotional Labour and Social Care

Emotions are fundamental to our lives and at the heart of social care (Gray, 2012). The sociological concept of emotional labour (Bolton, 2005; Bolton & Boyd, 2003; Hochschild, 1983) provides a perspective on personal emotion in the workplace that is particularly relevant to social care work and professional practice, not least because the development of relationships is core to the work (Eraut, 1994) and therefore demands emotional

engagement, often at a deep and personal level. The role of the frontline staff is often a varied one and encompasses diverse tasks such as administering medication, assisting with activities of daily living, managing challenging behaviour and facilitating the individual's inclusion in the community (Outar & Rose, 2017). The ability to cope with multiple and often competing demands has been identified as important to practice (Lazarus & Folkman, 1984).

Sowerby (2010) acknowledges the relevance of time and the influence that frequency, duration and intensity of contact have on relationship development and the emotional content of staff-service user interactions. This is a key issue in effective social care practice where staff engage with service users over long periods during which time significant empathy, respect and connections develop (Finnerty, 2012). If the emotions of staff are not properly managed this may impact on their performance as professionals (Hochschild, 1983). In an English study, Kadri, Rapaport, Livingston, Cooper, Robertson and Higgs (2018) found that the unacknowledged moral work of care reduces the staff's role to a series of tasks, impacting on their sense of self-worth and self-efficacy, and their ability to deliver person-centred care.

Emotional labour has its roots in the business world but is becoming increasingly acknowledged as an essential if undervalued element of the work done by caring professionals (Finnerty, 2012). Hochschild (1983) developed the original concept which focused on the exploitation of workers emotions for commercial gain. Core to Hochschild's (1983) view is the claim that workers are compelled to manage their own and other's feelings for the benefit of the organisation and to follow the organisations' feeling rules, which require either suppressing those deemed undesirable (e.g. anger) or portraying those that are expected (e.g. smiling). However, this conceptualisation is too simplistic and in response, Bolton (2005) proposed an alternative way of conceptualising, suggesting that employees control emotion in a number of ways: pecuniary (emotion management for commercial gain); prescriptive (linked to professional rules of conduct); presentational (governed by general social feeling rules); and philanthropic emotion management (where staff offer something extra to clients, representing everyday humanity in the workplace). The management of emotion is a multi-faceted process (Bolton, 2005), as Lewis (2005) describes that emotion management is complex and cannot be compressed into one category, individuals move between and across categories depending on context.

Staff can experience negative reactions in work which include dissatisfaction and stress (Mann, 2005), lack of openness with colleagues (Kahn, 1990) and burnout (Maslach & Leiter, 1997). These negative reactions are said to arise from the inauthenticity felt by staff needing to present one emotional reaction, while feeling another (Finnerty, 2012). Due to the demands of social care requiring a significant connection with service users and the building of a relationship, this interconnectedness leads to emotional involvement that requires emotion management. This is important, as Clements and Zarkowska (2000) assert that the patient, respectful and sometimes fraught work of supporting people with autism, is simply not possible within a service that cannot retain its staff.

2.4.2 Reflective Practice and Social Care

“Maybe reflective practices offer us a way of trying to make sense of the uncertainty in our workplaces and the courage to work competently and ethically at the edge of order and chaos. . .” (Ghaye, 2000, p. 7).

Reflective practice can be understood as the process of learning through and from experience towards gaining new insights of self and/or practice (Boud, Keogh, & Walker, 1996; Boud & Fales, 1983). This process often involves exploring assumptions of everyday practice and involves the practitioner being self-aware and critically evaluating their own responses to practice situations. The aim is to recapture practice experiences and mull them over critically so that new understandings are gained and future practice improves. This is understood as part of the process of life-long learning (Finlay, 2008, p. 1).

Clements and Zarowska (2000) assert that when staff supporting people who display behaviour which challenges them, their insights can be affected, particularly when the behaviour is personalised, for example, ‘she enjoys upsetting her housemates’. They recommend that staff remember and recognise the difficulty people with autism may have in understanding the thoughts and feelings of others, to help mitigate personalisation. It is important so, for services to recognise, that the management of emotions ensures the smooth running of organizations (Hochschild, 1983).

Reflective practice is often seen as the bedrock of professional identity. Reflecting on performance and acting on reflection, as McKay (2009) asserts, is a professional

imperative. Lalor and Share (2013) assert that a social care workers development depends on the quality of supervision, the philosophy of one's peers and one's ability to be self-reflective. In discussing the profession of social work, Banks (2006) asserts that critical reflection is an essential skill that practitioners need, to understand the complexities and contradictions inherent in the role of social worker, which no doubt has many similarities to social care work. It is reflective practice that shifts practice beyond trial and error, affirming that a reflective practitioner, a reflective framework and a reflective organisational culture enables effective practices (Gorman, 1998).

Banks (2006) notably points out that it is not always practical or desirable, to refer to an ethics rulebook for answers to ethical dilemmas in social work, arguing that the ability to critically evaluate and reflect are essential to practice. There are three types of reflection, which are: looking forward, looking at the present, and looking back, as well as many available models to aid reflection, but what is most important is that reflection is given time, space, structure and support to be developed (McKay, 2009). McKay (2009) advises individual practitioners and groups to choose a model that they find most useful and to also consider other methods of reflection such as telling stories and exploring critical incidents. Telling stories offers the individual an opportunity to reflect on an event or experience, making links to the past, present and the future. Critical incidents are not dramatic events or crisis situations, they can be small or common events that hold meaning to the individual or group, often because these incidents touch them at an emotional level. Furthermore, McKay (2009, p. 70) states that action must follow reflection, citing the words of Drucker, *"Follow effective action with quiet reflection. From the quiet reflection will come even more effective action"*.

2.5 The Organisation, Regulation and Management

The development of the Irish social care sector has been discussed previously, with social care services in contemporary Ireland being delivered by a variety of public, for-profit and non-profit agencies. Administrative and legal responsibility for most publicly funded services now rests with the HSE and the Child and Family Agency, with education and justice government departments also having a role (Howard, 2014). In recent years, the Irish social care and health system have experienced two significant developments, namely the establishment of HIQA and CORU under the Health and Social Care Professionals Act, 2005. HIQA has sparked developments concerning audit, quality

assurance, inspection and efficiency, as well as increasing the demands placed on managers to achieve and maintain a quality service (Featherstone, White, & Wastell, 2012).

Social care managers are now required to carry out self-assessments, offer data for analysis, submit documents for review, and prepare for inspections (Killeen, 2014). CORU's regulation of the new profession of social care, means that managers need to be well equipped with a solid understanding of the legal and regulatory frameworks, as well as the processes involved in the complaints system and requirements for registration (Jones & Carston, 2016). With the move towards individualised funding as a result of the HSE report *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* (2011), a key function of management into the future will be to manage the complexities of individualised funding arrangements for service users (National Disability Authority, 2011).

These evolving governance and management structures in social care work present a challenging workplace environment for staff and management (McCarthy, 2006). Whilst HIQA has created positive change for service users and for public trust (Killeen, 2014), Jones and Carston (2016) pose the question: *"have the regulators overburdened social care workers with bureaucratic procedures that are getting in the way of good quality 'relationship-based' practice, and can alternative leadership approaches bring the 'care' back into social care?"*.

It is within the context of all of these twenty-first century developments that the need to discuss the polarities between bureaucracy and increased regulation, and care arises (Jones & Carston, 2016). Smith (2016) fears that mandatory registration of social care workers will see Irish services mirroring practice in Scotland, where, he claims, too much faith is placed on systems rather than on people. In his address at the 2016 Social Care Ireland conference, Smith (2016) reflects on the complexity of relationships in practice settings and highlights the importance of young people in services experiencing love and connectedness. He claims, that this quality of care is difficult to acknowledge and account for in measurable sets of standards. This view is supported by the Department of Children and Families (2010) in the UK, where it was noted that even with standards in place, it was the quality of the relationships that determined whether the child felt cared for on a day-to-day basis. Perhaps a starting point might be to consider a different vocabulary in

relation to regulation, *“to help us frame what it is we do and what it is we hope. Perhaps it is time to put aside simplistic and individualized conceptions of rights, to put aside protection, risk assessment, ‘best practice’, codes, standards and to consider a vocabulary that speaks a different language with regard to children”* (Smith, 2010, p. 10), and perhaps too, adults with autism. Moss & Petrie (2002) offer a possible new vocabulary:

“Joy, spontaneity, complexity, desires, richness, wonder, curiosity, care, vibrant, play, fulfilling, thinking for yourself, love, hospitality, welcome, alterity, emotion, ethics, relationships, responsibility... are part of a vocabulary which speaks about a different idea of public provision for children, one which addresses questions of the good life”. (p. 79)

Relationship-based practice within social care often takes place in a relatively informal, extended and intimate space (Lalor & Share, 2013). The day to day shared life experiences with service users are a core part of social care practice and requires skill and professional wisdom to use these moments as opportunities for therapeutic change (Jones & Carston, 2016). It is no surprise then, that for relationship-based practice to become a reality in Ireland, practitioners will need time to develop their reflective capabilities (Smith, 2016), something which may be hard to reach due to the reported increased paperwork burden on social care managers and their staff teams (Howard, 2014).

Dent & Whitehead (2002) assert that in all of the social professions there has been a loss of public trust and an appetite for a sense of order due to an increased perception of risk. This focus on improving quality and minimising risk has been a focus for healthcare providers across Europe (Mendes & Fradique, 2013). European literature depicts a bureaucratic culture in the public sector with a strong emphasis on rules and regulations, where leaders are being challenged more and more to assume a main role in quality improvement and risk assessment (Mendes & Fradique, 2013). The Irish Association of Social Workers (Howard, 2011) propose that the culture of managerialism which has been creeping into the public sector, may be damaging rather than improving social work practice. Basu (2004) suggests that most social professionals rarely respond well to bureaucracy.

In the UK context, Francis (2013) highlighted the detrimental effects of a bureaucratic, target-driven system of management, where he witnessed an institutional culture and

leadership model that attributed more importance to the documenting of positive information about the service rather than information which was capable of indicating cause for concern. Following his findings, he suggests that a fundamental culture change was needed, beginning with leadership. Munro (2011, p. 48) commenting on how the UK has become overly dependent on procedures and paperwork, with frontline staff spending over 60 per cent of their time in front of computer screens, asserts that *“helping children is a human process. When the bureaucratic aspects of work become too dominant, the heart of the work is lost”*. Jones & Carston (2016) call for a similar audit of Irish social care services to ascertain the actual level of paperwork burden on staff and whether the level of bureaucratic tasks is getting in the way of social care workers building effective relationships with the people they support.

Now, more than ever, innovative leadership is needed to ensure that social care practice values (empathy, advocacy and respect) are realised by service users within the increasingly bureaucratic environment of social care (Mendes & Fradique, 2013). Laming (2003) rightly concludes that regulation has its place, but it cannot replace reflection, professional judgement and high-quality leadership. Smith (2009) calls for professional activism, professing that qualified, reflective, competent practitioners should not see themselves as victims of bureaucracy, but rather as leaders of reform in social care services of today.

2.5.1 Leadership

The question of leadership is as complex and difficult to pin-down as it is important to discuss (Van Zwanenberg, 2010). Within a healthcare setting, it was found that leadership actions such as communication, team development, recognition and innovation had a direct correlation with quality care (Mendes & Fradique, 2013). In establishing a person-centred culture, Loveday (2013, p. 43) states that *“person-centred leadership requires an open heart and an open mind; a commitment to honest and open reflection; a willingness to listen to feedback from all sources and recognise and admit where there are problems”*.

Many public inquiries have explicitly highlighted ‘over-bureaucratisation’ and failures in leadership as having restricted organisational capacity to promote the importance of quality outcomes and relationships in social care, with each report proposing radical new

approaches to leadership in the health and social care sector (Francis, 2013; Munro, 2011; Munro, 2010; Laming, 2003).

Laming (2003) stated that a leader's performance and effectiveness should be measured on the delivery of quality services to service users, rather than the maintenance of bureaucratic procedures. He insisted that strong leaders who engage their staff team in continuous examination to achieve quality outcomes for service users, together with effective decision-making, must replace bureaucratic administration. The *Victoria Climbié Inquiry* asserts that "*a healthy culture begins with high quality leadership*" where managers "*walk the talk*" and strive to listen fully to understand the difficulties facing front line staff (Laming, 2003, p15).

Jones & Carston (2016) propose that reflective practice and pedagogy through a combined model of leadership may provide a mechanism for Irish social care managers to fulfil their professional responsibilities. There is support in the literature for combining transformational, situational and pedagogical leadership approaches in social care services (Jones and Carston, 2016; Male and Palaiologou, 2012). A transformational leader actively engages with the team focusing on high-order intrinsic needs and raising consciousness about the overall mission, creating a vision for staff that motivates them to achieve that vision (Lynch, McCormack, & McCance, 2011). These leaders connect the team's identity with the organisation's identity, and base their role on trust, admiration, loyalty and respect for the staff team (Hafford-Letchfield, Lambley, Spolander, & Cocker, 2014). Situational leadership is an approach that is responsive to the needs of the worker. The leader is able to assess the performance, competency and commitment of each team member and respond in accordance to the needs or level of direction required by the team member (Hersey & Blanchard, 1982). Perhaps a practical step to implement this leadership style is to explore how staff engage in occupation and it's meaning for them. Cook et al (2016) advises that organisations audit frontline staff's own interests and skills, as by examining their own activity choices and the value that occupation adds to their own lives, they may be more likely to reduce experiences of occupational deprivation in the service users lives.

Finally, pedagogical leadership is supported around the world across a variety of human service disciplines. It facilitates the growth of a 'learning culture' within the workplace, where social care managers facilitate conversations with their staff to encourage

reflection, critical thinking and development of the professional wisdom required for quality human services (O'Donovan 2015; Male & Palaiologou 2012). It is argued that this approach to leadership would be beneficial for social care practice, where leaders would facilitate staff to examine their professional beliefs, responsibilities and actions in order to provide quality decision-making and care (Jones & Carston, 2016). It helps create a workplace culture that allows for honest and ethical conversations about practice, while empowering staff to take responsibility for their actions (Cheliotis & Reilly, 2012). Male and Palaiologou (2012) conclude that although social care is a bureaucratic profession where managers are primarily answerable to national legislation and policy, the pedagogical process facilitates team work, coaching and mentoring, allowing an organisation *"to tackle changes, to develop its vision and a new experience of learning based on sharing knowledge... and practice, and providing unconditional access to continuously changing resources for all participants, through collaboration and cooperation, in an atmosphere of openness and trust"* (Male & Palaiologou, 2012).

Perhaps similarities in services for people with autism can be drawn from Howard's (2012) suggestion that the *"incessant demands of bureaucracy mean that children exist in artificial, sanitised care bubbles where they are bereft of structure, empathy, spontaneity and real relationships. The very things they crave"*. Jones and Carston (2016) offer the solution of a pedagogical leadership approach to Howard's (2012) fears for children in services.

Furthermore, Haines and Brown (2017) state that professionals should collaborate by providing effective leadership, work in partnership with support workers and managers while simultaneously recognizing the influence of organisational structures and context. They conclude that the findings of their study are reflexive of the essential components of teamwork and suggest that it may be helpful for professionals to view themselves as part of the team with support workers. Perhaps this view may be supported by occupational therapists working in services, given the central component of collaboration within occupational therapy. This view is supported by other authors, who suggest an approach of combining learning in context with collaborative leadership, empowering staff, by flattening hierarchies, modelling, problem-solving and regular presence to make complex ideas accessible (Northouse, 2013; Storey & Holti, 2013; Hackman, 2002).

Haines (2015) concludes that as occupational therapy intervention may always be time-limited, the focus should be on creating and maintaining cultural change within the organisation, to support the authentic occupational engagement of its service users. So, occupational therapists should view support staff as client's in a similar way to the people with autism who will ultimately benefit from the intervention. The occupational therapist should aim to empower staff to take on a different way of working, through a collaborative, unthreatening relationship with staff and managers, where creative and flexible interventions spark creativity in staff members (Haines, 2015). Therefore, Haines (2015) suggest that occupational therapists should take on the role of transformational leader, who is *"an agent for change and good role model who can inspire others to achieve higher standards by articulating a clear vision, while at the same time encouraging one or more of the support workers and managers to take on this role"* (p. 308).

Leaders who possess the aforementioned combination of leadership approaches and skills will be able to facilitate a shared vision, stimulate learning and reflection through the use of coaching conversations to support the complexities of practice, supervise within a situational and responsive nature and balance accountability with a refocus towards care (Jones & Carston, 2016). Plesk (2017) states that leaders should adopt just a few simple rules, abandoning hierarchical control and encouraging professional autonomy. Munro (2011) emphasised the importance of leadership to enable staff to use their professional judgement and to embrace the staff's ability to be skilled in relationships. This reflective and relationship-based practice should be embraced by social care managers and can become a reality through effective leadership (Munro, 2010).

2.5.2 Culture

After discussing different elements of an organisation such as staff emotion, the management of emotions, reflective practice and effective management and leadership approaches, the problem of collective disorder within organisations is presented.

Walker (2008) states that one of the key functions of an organisation is to act as a secure base, as the more secure a social care worker feels about their organisation, the more likely they will be able to do their work well. As alluded to previously, the personal impact of the work of caring for other human beings can create an emotional strain, often not spoken of much and met with an attitude of indifference. This strain is considered simply

part of the work, an emotional labour (Hochschild, 1983). If the organisation makes no effort to support this strain on its workers, Hinshelwood (2012) states that the result might be an unexpected 'pathology' of the organisation, which manifests as institutionalisation in old mental health hospitals, and as social isolation and passivity of clients in the new community care model. The combination of this strain and an attitude of silence from the organisation, might amount to a stress in staff that reaches the level of trauma, leading to clear maladaptive behaviour, of which some aspects are known as burnout (Maslach & Leiter, 1997).

Hinshelwood (2012) presents a discussion on the personal trauma of working in psychiatry and the collective disorder that can occur within organisations, framed within a psychodynamic perspective. First, the belief that it is the size of the institutions that cause passivity, depersonalisation and institutionalisation is opposed. Leff (1997) states that the move from large institutions to community care, offers a degree of deinstitutionalisation, but to a very small effect. Iriarte, Stockdale, McConkey, and Keogh (2016) more recently warn about simply moving institutional practices from larger institutions to community-based services. Hinshelwood (2012) offers a new hypothesis, that the crucial factor appears to lie in the dynamics of the delivery of care in various structures and therefore, in the nature of working with people with psychotic illness. Such is the importance then, of discussing this concept within an organisation supporting people with autism, in an era where services are in a period of change in the move towards person-centred supports.

It is precisely down to the reasons that make us work with people with disabilities or mental health difficulties that we can be so vulnerable. Invariably, staff begin their working lives with a special wish to help (Roberts, 1994), a strong engagement and sensitivity, with big aspirations of restoring people from poor states, back into whole and happy persons. However, in reality, staff satisfy this need with only a small number of people, leading to a sense of failure (Hinshelwood, 2012). Mental health workers are too often left with people who remain permanently un-helped. These experiences lead to feelings of inadequacy and unfulfilled responsibility, and ultimately, the phenomenon known as burnout. A significant and painful gap can open between the expected achievement and the realistically achievable, leading to acute personal difficulties, going unrecognized, resulting in an acutely lonely staff member in danger of burnout. This

pressure can be felt among service users, with a demand on the person to change or be well, for the sake of the staff member (Hinshelwood, 2012).

The varied characteristics of people with autism and the demands associated with the support required, mean that their support workers face persistent challenges and are prone to burnout (Lovell & Wetherell, 2016; Lovell, Elliot, Liu, & Wetherell, 2014). Smyth, Healy, and Lydon (2015) conclude that the frequency and severity of challenging behaviour experienced by support staff is related to the perceived stress of disability support workers, and hold predictive power for two facets of burnout, emotional exhaustion and depersonalisation. This demand, or strain, faced by these support workers is exacerbated when their psychological capital (self-efficacy, optimism, hope and resilience) is low, which is often associated with decreased emotional exhaustion and psychological well-being (Manzano-Garcia & Ayala, 2017). Manzano-Garcia and Ayala (2017) emphasise the importance of strengthening the psychological capital of the support staff of autism services, which will in turn, help them to improve their professional effectiveness, lessen feelings of emotional exhaustion and the use of cynicism as a coping mechanism in their day to day work.

Hinshelwood (2012) asserts that staff can cope with the 'numbing strain' to a limit, but beyond that they quickly institutionalise an emotional distance, regardless of a large institutions' walls or the context of the wider community. *"If we reduce the 'person' of the patient/client, we thereby reduce the emotional impact of 'failing' them"* (p135). The stressful experience of the work can invade staff, and although it may be dealt with by a kind of 'not thinking about it', the impact, at an unconscious level, is sufficient to distort the work. Thus, the staff team and a whole service can be said to be affected by a process called countertransference (Hinshelwood, 2012). An individual staff members disturbance, distorts personal and group functions, but it can also promote sets of maladaptive cultural attitudes in the organisation as a whole, such as demoralization; stereotyping of patients; scapegoating; meaningless routines; paranoia; splitting and fragmentation among staff groupings; fragmentation of the wider agency; social defence systems and an anti-task attitude (Hinshelwood, 2012).

It has been argued that some aspects of the institutionalisation in the old hospitals have transferred over to community care. Hinshelwood (2012) argues that a number of the characteristics of community care can drift into maladaptive anti-tasks and might

represent social defence systems, such as, professionalised care; skills-based training; risk management; care and 'narcissism'; survival anxiety; and incohesive multi-disciplinary teams. These characteristics may arise alongside problems such as absenteeism and high turnover rates, together with a restless series of policy changes, such as risk management.

Hinshelwood (2012) states that such self-defeating organisational effects could appear in any high-stress occupational organisation, making this discussion relevant to organisations supporting people with autism. Martin & Henderson (2001) explain that values are deep seated beliefs about what is right and wrong, and what is important and unimportant. An organisations values are influenced both by values held by the world in which it exists, by those held by the staff, and those who use its services. It is important to know that this influence does not only pass one way. The individuals also influence their groups, their organisation and the society in which they live (Martin & Henderson, 2001). Hence, it is essential that the reality of care is robustly acknowledged, as the silence results in extra harm to the functioning of the service as a whole (Hinshelwood, 2012). *"Breaking the silence and engaging in shared recognition of the numbing encounter at the heart of the work, the limited achievements, and the real benefits of meagre improvements, could release many teams from demoralization and fragmentation"* (Hinshelwood, 2012, p. 146).

2.6 Conclusion

Supporting the occupational engagement of people with autism is a priority. In Ireland today, people with autism are being supported by social care staff within organisations striving for person-centred care. Although there is considerable literature that supports using a person-centred approach to practice, there remains many challenges to its implementation within organisations. It is acknowledged in the literature, that the management of emotions of social care staff is imperative to the person receiving a high-quality service. This requires organisations to have good leadership and staff support in order for the occupational engagement of adults with autism to be supported. It is critical that the organisation is a sound base for its social care staff.

Chapter Three – Methodology

3 Methodology

3.1 Aim of the Study

The aim of this study is to explore staff members' support with adults with autism in occupational engagement in their daily life.

The research objectives are as follows:

- How do staff offer support to service users in participation?
- How do staff offer support to service users in their daily routine?
- How do staff offer support to service users in communicating in their everyday life?
- How do staff offer support to service users in social contact within day to day routines, hobbies and interests?

As discussed in the literature review, not all staff working in human service organisations have qualifications in social care (Finnerty, 2012) and have a wide array of experience and varying skill sets. This is reflected in the participant groupings within this study, such as one garden participant whose role developed naturally as he invited people with autism to work alongside him (described further in section 4.2.1). Each participant's individual story is described in Appendix E.

The research objectives allowed the exploration of factors affecting staff in their support of adults with autism. Semi-structured interviews were used with staff working with service users with autism. Staff in this study were categorised into one of three groupings:

- Day service staff
- Residential staff
- Garden and maintenance staff

3.2 Research Design

Qualitative methods allowed for a more holistic view and deeper understanding of the research topic (Silvermann, 2016) in which the unique experiences of each staff member could be reached and examined. The primary goal of qualitative research is the naturalistic discovery, identification, and description, of basic features of the worlds people live in, and their unique experiences of those worlds (Luborsky & Lysack, 2006)

Qualitative research emphasises the subjective, or ‘emic’ perspective of individuals which is shared by the occupational therapy profession in its culture, if not always in practice (Cook, 2001). Thus, qualitative research methodologies are suitable for researchers who wish to gain an understanding of people as occupational beings (Cook, 2001).

A study by Iriarte et al (2016) examined staff and service user’s perspectives of their move out of congregated settings and into housing in the community. A semi-structured interview process was used to elicit the opinions and lived experience of the transition of both staff and service users.

The researcher in the current study chose to use the qualitative descriptive method of qualitative research, with the aim of remaining close to the data and to present a straightforward description of the staff members perspectives (Sandelowski, 2000). Sandelowski (2000) states that *“qualitative descriptive designs are typically an eclectic but reasonable and well-considered combination of sampling, and data collection, analysis, and re-presentational techniques”* (p. 337). Sandelowski (2000, p. 337) holds that qualitative work is not produced from any “pure” use of a method, but are created through the use of methods that are *“variously textured, toned and hued”*. This qualitative descriptive study arguably has overtones of the phenomenological approach.

Thematic analysis was chosen as a method of data analysis for this study, a flexible approach that can be used to reflect reality, and to unpick or unravel the surface of ‘reality’ (Braun & Clarke, 2006, p. 9). A detailed description of data analysis is given in Section 3.6. Ethical considerations were addressed at all stages of the study (described in Section 3.8).

3.3 Research Study Site

3.3.1 Physical Environment

This section describes the physical environment of the various locations within the disability service setting, which is comprised of larger day centres, smaller hubs, residential houses and the wider community.

3.3.1.1 Day Services

One of the day service locations is in a period of transition and building works, where the old-style larger day centre is being split up into smaller hubs, in an attempt to align itself with the outreach day service model. So, the physical environment of day services at the time of this study was quite disruptive, where service users and staff were moving out to allow the building work commence.

The outreach day services operate out of rented houses in the community. One of these houses is comprised of offices on the upstairs floor and downstairs is used as meeting or activity space where staff hold sessions with service users. The other outreach day service team work in 'hub' style spaces, where rented houses in the community are used as day service for approximately four service users daily. The hubs are made up of kitchens, living areas, sitting rooms, and activity rooms which were converted from bedrooms.

3.3.1.2 Residential Services

The first residential environment is that of group homes. Both group homes discussed within this study were located on the organisation's central campus, which also has a day centre, one other group home, a number of single occupancy apartments and a large walled garden onsite. Each resident has their own bedroom, with shared bathrooms and living space. The environment contains many visible influences of regulation which increase the institutional feel of the house, such as fire exit signs, complaints procedure documents hung on the wall, visitor books and mandatory colour coded chopping boards. In addition, due to the number of people living in the houses and the individual needs of each person, various restrictive practices are in place, such as locked doors and cabinets.

The outreach residential environment differs, in that the support provided to the person, is within their own home, where the person is living by themselves. However, the environment contains the same institutional items as mentioned above in order to comply with the regulations. There is a designated staff bedroom in each of these houses.

3.3.1.3 The Garden

The garden is a large walled garden, which has a large polytunnel, vegetable plots, chicken coop, a tree house and a number of work sheds containing kitchen facilities and a toilet. The garden is accessible by path from a number of exits from the various buildings such as

the day centre and each of the residential homes. The garden is sprinkled with the creative work of service users, with painted furniture and wall hangings.

3.4 Sampling process

3.4.1 Inclusion and Exclusion Criteria

Any staff member of the service working directly with an adult with autism to support them to live their day were invited to participate in the study. Full-time, part-time and relief staff were invited to participate. All residential, day service and garden and maintenance staff members were invited to participate.

The researcher's reflections on the everyday interactions of service users and staff within the service highlighted the need for all staff in contact with service users throughout the day to be invited to participate. This is described in the following excerpt from the researcher's reflective diary:

"Just after the gatekeeper had dropped the information leaflets to the workshop in the garden, one staff member came to me and asked "are those just for staff or who are they for... The maintenance guys said it's nothing to do with them". Just as she said this, screaming and laughing came from down around the workshop. We looked down, the staff member said "Oh don't mind them, they're playing with water guns down there". I realised then that the noise was coming from the maintenance men and a service user who works in the garden. I said to the staff member "that is why this research needs to include everyone". (Reflective Diary, November 2017).

Staff members who did not work directly with service users with autism were excluded from participating in the study.

3.4.2 Sample Size

In qualitative research, there are two principles that guide qualitative sampling: appropriateness, and adequacy (Morse & Field, 1995). Appropriateness relates to the identification of participants who will best inform the researcher about the topic under examination (Dickerson, 2006). For this qualitative descriptive study, purposive sampling was used to obtain participants who were deemed information-rich (Sandelowski, 2000) in relation to supporting the occupational engagement of adults with autism. It allowed

for the recruitment of a certain category of people with unique, different and important perspectives on the topic in question (Mason, 2002). Purposive sampling is a non-random way of ensuring that this particular category of participants was represented in the sample (Robinson, 2014). Staff members supporting adults with autism in occupational engagement in daily life were invited to participate.

Adequacy of data means that enough data will be available to elicit an in-depth understanding of the research topic (Dickerson, 2006). This knowledge, along with practical clinical reasoning (Boyt Schell, 2014), indicated that an adequate sample size was reached when at least two staff from the three different practice sites were represented, that is, those working in day services, residential services and in garden and maintenance services.

A total number of 207 staff were employed within the service at the time of recruitment. The sample size of the study was eight.

3.4.3 Recruitment Process

Participants were informed of the research study through posters displayed in staff areas of the service locations. The Letter of Invitation to Participate was circulated at this time to all staff sites of the service. Staff were invited to contact the researcher to express their interest and request further information on the study.

Once participants expressed interest in the project, the researcher met participants individually and provided a participant information leaflet and a consent form. At this point, the researcher was available to answer any questions that potential participants had regarding the research project.

A period of at least seven days was given before the researcher made the next contact with the potential research participants. This afforded the participant time to consider taking part in the research study. Participants who decided to take part in the study and complete an interview, set a date for interview during the next meeting with the researcher. The participants signed consent forms prior to each interview.

3.5 Data Collection Methods

Data collection took place over the course of one week in December 2017 and two weeks in January 2018. Data collection in qualitative descriptive studies typically include minimally to moderately structured open-ended interviews (Sandelowski, 2000).

3.5.1 Rationale for Choosing Interviewing as the Data Collection Method

Interviews were chosen as the data collection method as it allows the researcher to gather the participant's own experience and opinion of the research question. Semi-structured interviews were selected as they provided structured questions but also the opportunity for the participant to elaborate and give details about their experiences (Taylor & Francis, 2013) of supporting the occupational engagement of adults with autism in their daily lives.

"If we wish to learn how people see their world, we need to talk with people"

(Liamputtong, 2013, p. 51). Gubrium, Holstein, Marvasti and McKinney (2012) propose that interviewing is a means of collecting empirical data about the social world of individuals, by welcoming them to talk about their life experiences in great depth.

This level of data may not be achieved during a focus group. Due to the nature of group talk, people may not feel comfortable sharing certain experiences and perspectives, or may conform to the responses of other participants, whether they agree or not (Liamputtong, 2013). In comparison, during an interview, the researcher is able to elicit the individual's unique interpretations of the experience of supporting people with autism. The researcher must recognise that knowledge is situated and contextual (Mason, 2002), so the context of supporting the occupational engagement of adults with autism, must be brought into focus so that situated knowledge can be produced by the participants.

Preparing for and undertaking interviews is not simple or straightforward, and requires the researcher to grapple with technical and epistemological issues in order to achieve trustworthiness (Taylor & Francis, 2013). Thus, in this case, the research supervisor who completed the interviews was an experienced interviewer, with many years of research experience within occupational therapy and services for people with disabilities.

3.5.2 Designing the Interview Guide

The conceptual model underpinning this study, the Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2007) was used in developing the semi-structured interview guide. Pragmatic clinical reasoning (Boyt Schell & Schell, 2008) influenced the inclusion of some questions and themes in order to elicit the day to day actions of staff members supporting the occupational engagement of adults with autism in their day to day lives.

In developing the interview guide, in conjunction with CMOP-E and clinical reasoning, the researcher used an occupational engagement framework to decide on the questions to be included. Occupational engagement involves engagement in all kinds of everyday activities and relates to the degree to which a person; experiences a sense of meaning from occupation, has a variety of occupations that create a daily rhythm, initiates occupations, interacts with other people and acts independently (Tjornstrand, Bejerholm, & Eklund, 2015).

A number of central beliefs from occupational therapy theory, relating to occupational engagement influenced the development of the interview guide. Meaning, choice and motivation are central to occupational engagement (American Occupational Therapy Association [AOTA], 2014), implying that it is a wholly person-centred process. Occupational therapy views engagement in occupation as a basic need, and so intervention with people must be occupation-focused (Townsend & Polatajko, 2007).

In addition, collaborative relationships are considered vital to understanding the person's experiences and desires for occupational engagement. A collaborative approach values the person's contributions and allows a shift in power in the relationship to allow control in decision making by the person (AOTA, 2014), essential for occupational engagement. The CMOP-E recognises that engagement in occupation is context dependent, where the environment impacts on occupation and in turn, occupation impacts on the environment (Townsend & Polatajko, 2007).

Guided by the above concepts, taken from occupational therapy theory, the researcher decided to use an Emic technique. An emic perspective, "*the insider's view*" is at the heart of this research project, as it helps the researcher to understand why people do what they do (Morse, 1994, p. 166). In this study, the researcher values how the person tells their story, as well as what they have to say. In order to gain optimum depth and reflection from the research participants, the researcher provided the interview guide prior to the

interview date (Lysack, Luborsky, & Dillaway, 2006). This allowed the participants time to review and reflect on the questions.

3.5.2.1 Initial development

Initially, the research study was designed to be carried out using a two-stage interview process. The interview template was developed for use with staff coming from all service backgrounds. No distinction was made between staff from different backgrounds as all of the questions were deemed relevant to frontline staff in all areas of the service. The interview template was reviewed (Kielhofner, 2006) by a Social Care Leader working in the service, who was independent of the study as she had not volunteered to take part. The social care leader had nine years of experience supporting adults with autism, in both residential and day services.

3.5.2.2 Pilot stage

The initial interview template was piloted with an Outreach Support Worker working within the service. The support worker was able to advise on wording of questions as she understood what her colleagues were likely to understand. The support worker advised on language that would be accessible to the research participants who did not have an occupational therapy background.

Following pilot interviews one and two, the researcher and the research supervisor decided not to complete the interview in a two-stage process. It was decided that two separate interviews were not necessary to elicit the information needed from the participants, that the interview would flow better if both interviews were completed in one, and that it would be possible to complete in 30-40 minutes in total.

3.5.2.3 Final Templates

Following the pilot interview, a final set of changes were made to the interview guide and interview process. The final interview guide was structured around the themes described below.

Part One:

Background

The first set of questions within the interview, were used to help to put the participant at ease. They are concrete questions that the participant should have no difficulty in answering, for example, how many years have you been working in this area; and how many service users do you support at any one time. They are straight forward questions that should help the interviewer to get a sense of the participants working background and of their current day to day job.

Part Two:

Hobbies

In an effort to help the participant to feel at ease, the researcher aimed to first ask about how the participant supports adults with autism to engage in their hobbies and interests. Asking questions about an individual's leisure pursuits, gives the researcher an idea of the service user as an individual, an occupational being. This question gives the research participant an opportunity to give a picture of the person and what they enjoy doing and perhaps what may be interpreted as occupational engagement. Within the regulations and standards of HIQA (2013) and the policy of New Directions (HSE, 2015), supporting people's hobbies and interests is expected of staff working in disability services. So, it is shared knowledge between the researcher and the participant that this is a significant part of their job description, and so this question should be settling for the participant.

Routine

The next question deals with routine, that of the person, of the work environment and how both routines interact. This question looks to find out how and where the person sits within the routine of the environments of the different types of services. This will give the researcher an insight into the routine of the service environment, if it has an institutional nature, the use of staff and service users' time, and staff management of the service user's time. This will provide insight into the occupations that provide a daily rhythm for the person as discussed within occupational engagement (Tjornstrand, Bejerholm, & Eklund, 2015).

Communication of Needs

This question asks the participant about how the person communicates their needs. This offers an opportunity to explain how they understand the importance of communication. It may offer an opportunity to express how people with autism may communicate in an

idiosyncratic way. This will provide an insight to the researcher about the relationship between the person and the staff, and if it is of a collaborative nature (AOTA, 2014).

In addition, the researcher will gain insight into the kind of needs that are talked about, whether the focus is on self-care, productivity, leisure, or spirituality (CMOP-E). Maslow's hierarchy of needs may be used as a framework for interpreting needs discussed e.g. are they Deficiency Needs: physiological; safety; belonging and love; esteem; or, Growth Needs: cognitive; aesthetic; self-actualization; and transcendence (Maslow, 1970a; Maslow, 1970b).

Social

This question offers the participant an opportunity to explore the service user from a social perspective, their social likes, dislikes and opportunities for social contact in their day to day lives, and what they do to support this. This may provide insight into how staff perceive and understand service users in different social settings. It will address context, specifically the social environment around the person, as described by staff (Townsend & Polatajko, 2007).

Part Three:

The third part of the interview was guided by the list of questions detailed on the interview guide. This list of questions is used to gain an understanding of the participants' professional practice reasoning, in supporting occupational engagement. This list of questions will give the researcher an insight into what is guiding the participants' professional practice.

In the absence of universal consensus on what social care is, the Irish Association of Social Care Educators (IASCE) defines social care as *'a profession committed to the planning and delivery of quality care and other support services for individuals and groups with identified needs'* (as cited in Lalor & Share, 2013, p. 4). Campbell (2015), discusses two distinct models of social care practice which she terms 'the voice of care' and 'the voice of justice', stressing that much thought needs to go into developing a framework for professionalising social care. These questions may highlight the current frameworks staff are using when supporting adults with autism.

O'Hara (2012) asserts that reflective practice can be the cornerstone for frontline staff by preparing and enabling them to be competent and capable of creating a better life and society for the people they work with. The researcher will gain an insight into whether or not the important routine of reflective practice is something carried out by the staff in their work with adults with autism. This may highlight factors relating to the cultural environment of the service.

The researcher will gain an insight into the person within the environment, and the person – environment fit. Factors relating to the sensory environment may be eluded to by the research participants during the interview.

These questions will provide more in-depth information about the person with autism, and the relationship between the staff and the person. The researcher will be able to further explore if the relationship is collaborative, where partnership and joint decision-making feature (AOTA, 2014). Furthermore, there will be an opportunity to explore if the person is happy with the various activities described by the research participant, and how this is interpreted and viewed by staff. This will provide information on whether staff adopt a person-centred approach to practice; a concept core to the philosophy of occupational therapy (Canadian Association of Occupational Therapists, 1997).

Figure 2: Interview Guide



TRINITY COLLEGE DUBLIN
COLÁISTE NA TRÍONOIDE, BAILE ÁTHA CLIATH

THE
UNIVERSITY
OF DUBLIN

Service Logo

Interview Guide

Background:

1. How many years have you been working with adults with autism?
2. How long have you been working in this service / service setting?
3. On average, how many service users with autism do you support at any one time/during one shift?

Tell me about...

4. How you support a service user in participation in their hobbies and interests?
5. How you support a service user in participation in their daily routine?
6. How you support a service user in communicating his/her needs?
7. How you support a service user in social contact through different activities?

The interviewer will ask questions such as:

- Why do you support the person in this way?
- Tell me more about how you support the person during that task/activity
- What are your thoughts when you support the person in that manner?
- How do you prepare for this engagement yourself?
- How do you plan your interaction with the person?
- How do you give support during the activity?
- How do you plan for your use of materials and equipment?
- How do you think about the physical, social and sensory environment?
- How do you know what works for the individual service user?
- How do you know the person is happy with this?
- What about if things don't go well, or work out as you had planned?
- Do you feedback to others about the engagement and the supports?
- How does this fit in with your routine; other duties; reporting and record keeping?
- Is there anything that would help?

3.5.3 Conducting the Interviews

The research supervisor conducted the interviews. The researcher and the interviewer engaged in a reflective interview practice, where the interviewer's own talk was examined, leading to mindful consideration of the interviewer's role in the generation of data (Roulston, 2010). Sacks (1992) makes an insightful observation that conversational sequences cannot be predicted, a perspective that is supported in the current study and strengthened as the researcher did not carry out the interviews herself. The interviewer commented that:

"The questions asked about the anticipatory role of the staff members regarding their mindset and how they prepare themselves for the work setting became valuable in getting an understanding of the core of the study. Thus, following the first number of interviews, these questions became more prominent in the interview. Although such questions are quite conceptual, they seemed to make sense to the participants and provide a reference point as to the purpose of the study itself" (Interviewer Reflection, January 2018).

While the literature on qualitative interviewing advises on various 'best' practices that interviewers should follow, there is no way of predicting what will happen in any given interview (Roulston, 2010). *'Good' questioning practices at times do not generate rich, descriptive data* (Roulston, 2010, p. 147), and in this study, the interviewer acknowledged this and engaged in a process which allowed each individual participant to tell their individual story.

3.5.4 Face Validity

Face validity ensures that the instrument i.e. the interview template, fully addresses the research question, and that data analysis methods are carried out appropriately to ensure full trustworthiness (Richards & Morse, 2013). Face validity was accounted for in the questions within the interview guide directly relating to how staff support the occupational engagement of adults with autism in daily life. In addition, the methods used i.e. qualitative methods, were an appropriate fit to answer the research question, as the researcher is asking for the participants individual experiences and perspectives of the research question (Taylor & Francis, 2013). Face validity alone is not sufficient to ensure trustworthiness, so content validity is discussed.

3.5.5 Content Validity

Content validity relies on the researcher having a clearly defined idea of what it is they want to measure, ensuring that the content of the instrument i.e. the interview template, relates to the research question under investigation (Breakwell, Hammond, Fife-Schaw, & Smith, 2006). Content validity is achieved when the instrument contains appropriate 'content' for measuring the construct, that is that the questions asked are appropriate for measuring how staff support adults with autism in occupational engagement (Bernard, 2012). It too addresses whether the content of the qualitative research effectively and comprehensively reflects the perspective of the population of interest (Brod, Tesler, & Christensen, 2009). The initial interview guide developed was reviewed by a Social Care Leader within the organisation who was independent of the study and had nine years of experience supporting adults with autism. She reviewed the interview guide using questions (Kielhofner, 2006) such as:

- Are the questions clear to be understood easily by the intended population?
- Are the questions included relevant? Are there any that are redundant?
- Are there any important questions not included?
- Rate questions from most important to least important.

In addition, the content of the interview questions needed to be broadly based and flexible to allow for varying degrees of relevance to the individual participant due to the differing contexts in which the participants worked. This was to ensure that valuable information from each participant could develop sufficiently for a satisfactory response to the research question. The participants needed this time and flexibility from the interviewer to tell their individual story. Sandelowski (2000) writes that *"knowing any phenomenon requires, at the very least, knowing the 'facts' about that phenomenon. Yet, there are no 'facts' outside the particular context that gives those facts meaning"* (p. 335). The researcher acknowledged this in how the interviews were conducted, allowing the participant to describe and discuss their answers to the questions, with particular concern for their individual context.

3.6 Data Analysis

Eight interviews in total were carried out with staff members, over a period of one week in December 2017 and two weeks in January 2018. Following each interview, the

interviewer noted down initial reflections and thoughts about the interview. This assisted the researcher in completing coding and data analysis at a later date.

Thematic analysis, often used in qualitative descriptive studies (Vaismoradi, Turunen, & Bondas, 2013), is *“an accessible and theoretically-flexible approach to analysing qualitative data”* and was chosen to analyse the data gathered from the semi-structured interviews (Braun & Clarke, 2006, p. 2). Thematic analysis is useful as it highlights commonalities and differences between people concerning dominant themes within the data set (Breakwell, Hammond, Fife-Schaw, & Smith, 2006). This is achieved by first generating codes for the data which is followed by the emergence and development of themes.

In order to elicit a rich thematic description of the entire data set, the researcher used an inductive approach (Ryan & Bernard, 2003). This is useful when researching topics that are under-researched. The advantages of this approach are that the researcher does not try to fit data into an existing coding frame, instead the analysis is data driven (Braun & Clarke, 2006). Despite using an inductive approach, the researcher was aware that she could not entirely free herself of prior assumptions relating to the research topic (Braun & Clarke, 2006), and so adopted the use of a reflective diary to reduce the influence of this factor.

Data analysis was completed using the structure and format for thematic analysis described by Braun and Clarke (2006), involving a six-stage process where the data is first analysed into codes, and then themes. The researcher used the data analysis package NVIVO (QSR International, 2018) to support the data analysis process, as outlined below.

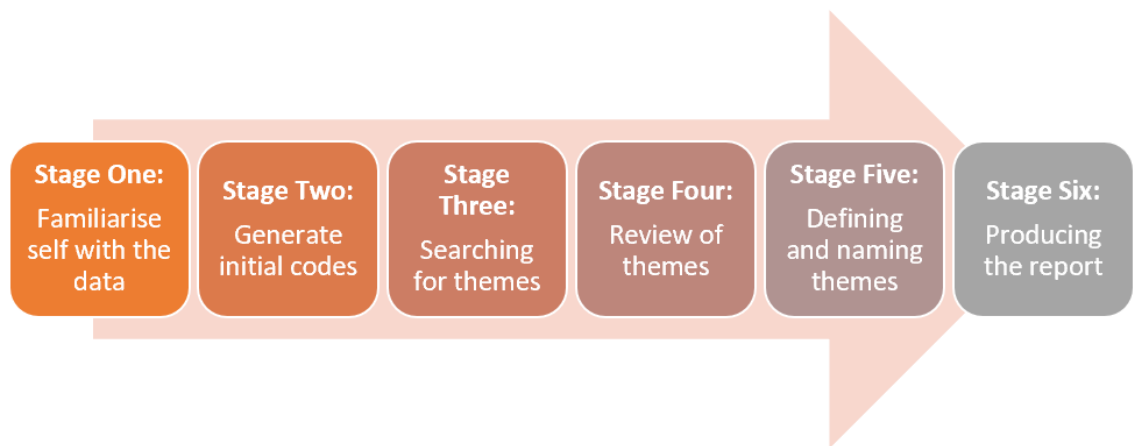


Figure 3: Data Analysis Process (Braun & Clarke, 2006)

1. Researcher familiarises self with data

The data was not transcribed by the researcher in order to maintain confidentiality for participants. The researcher immersed herself in the data by reading and re-reading each of the interviews, while at the same time making initial notes and writing down ideas for coding in the margins of the transcript (Braun & Clarke, 2006). The researcher then compiled a list of ideas about what was in the data and what was interesting about those ideas. (Braun & Clarke, 2006). This provided the researcher with a thorough understanding of the data in order to move to the next phase of the analysis process.

2. Generating initial codes

This phase was enhanced by the initial reading of the data and the list of ideas written by the researcher. The researcher produced initial codes from the data, by identifying interesting features within the data and applying codes to a segment or element of the data. This process involves organising the data into meaningful groups (Boeije, 2010). As the researcher intended for the study to be data-driven, the codes came directly from the data to produce the themes (Braun & Clarke, 2006). The researcher was mindful to code for as many potential themes and patterns as possible, remembering that the data set would not be without contradiction and the tensions and inconsistencies within the data set were recognised (Braun & Clarke, 2006). This phase of the process was completed using a software package, in order to ensure none of the data could be lost.

3. Searching for themes

The third phase of the data analysis process began once the researcher had coded the entire data set and had a long list of the various codes identified within the interview transcripts. This phase involved sorting the many codes and gathering all relevant coded data extracts into the potential themes. At this stage, the researcher stopped using the software program and began to organise the codes visually using paper, by cutting the various codes and labelling the back with the participants identity code. The small pieces of paper were then grouped together into various different potential themes, as the researcher constantly analysed the theme groupings and created overarching themes and sub-themes from the initial codes. Ryan and Bernard (2003) refer to this process as “cutting and sorting”.

4. Reviewing themes

The researcher began this phase with a collection of candidate themes and sub-themes with all extracts of data on individual pieces of paper within the theme ‘piles’. The researcher reviewed each of the individual themes, ensuring that all coded data within the theme matched together meaningfully and that there were clear and identifiable distinctions between each theme (Braun & Clarke, 2006). This involved two levels:

- Level One: The researcher reviewed the data at the level of the coded extracts, ensuring they form a coherent pattern within the theme. Following this, the researcher created a visual thematic map, as shown in Section 4.3.
- Level Two: The researcher returned to re-read the entire data set with each of the individual themes in mind, checking for the validity of each theme in relation to the data set. In addition, the researcher completed this process in order to check for any additional codes that may have been missed in the initial coding stages.

5. Defining and naming themes

The fifth phase involved defining and further refining the themes. The researcher further analysed the data within each theme, identifying the ‘essence’ of what each theme is presenting, and creating sub-themes where necessary, as shown in Figure 5 in the following chapter. At this stage, the researcher discarded the working title of

each theme and decided on five names that would be used in presenting the final report.

6. Producing the report

The final stage of the data analysis begun as all themes had been thoroughly examined and refined, and the researcher could begin to write the results of the research study in a non-repetitive, concise, coherent, and logical manner.

3.7 Trustworthiness

Lincoln and Guba (1985), long ago stated that trustworthiness is simply about how the researcher can persuade their audience that their study's findings are worth paying attention to; worth taking account of. There are many strategies that may be used in order to establish the trustworthiness of a research study, for example: credibility, transferability, dependability, and confirmability.

3.7.1 Credibility

Jensen (2008) defines credibility as "the methodological procedures and sources used to establish a high level of harmony between the participants' expressions and the researcher's interpretations of them". The researcher used the following methodological procedures to increase credibility (Jensen, 2008):

- **Angles:** the researcher utilised different perspectives and viewpoints, by completing interviews with staff from different models of service, to get a holistic picture of the environment
- **Colleagues:** the researcher used an individual knowledgeable in the area to review and critique the interview guide. The researcher also used the resource of her supervisor, a person who has years of experience working with disability services supporting people with disabilities, intellectual disabilities and autism.

During the early stages of her post, the researcher held assumptions of residential staff, assuming they were not thinking about person-centred care or implementing person-centred plans. The researcher assumed that staff did not have an occupational perspective on their work, and assumed they offered little meaningful activity choices to the people that they supported. Here, the researcher clearly states her bias within the research study, given her on the ground experience within the research site and her

previous assumptions held about staff members working in the various work site locations.

3.7.1.1 Reflective Diary

A reflective diary was used to increase credibility of the study, as although qualitative research provides an account of the participants perspectives and experiences, the researcher is inherently intertwined in the process of data analysis (Cohen & Crabtree, 2008). The researcher kept a reflective diary throughout the entire research process, as a means of discussing the *“presumptions, choices, experiences, and actions during the research process”* (Mruck & Breuer, 2003, p. 3). It facilitated the researcher to acknowledge how her experience working in the service, and her own professional assumptions and values, influenced the research topic, process and the presentation of findings (Ortlipp, 2008). Qualitative researchers acknowledge the influence of the reactions and perspectives of the researcher within the research process, and accepts that this ‘bias’ cannot be eliminated, and in fact, should not (Lysack, Luborsky, & Dillaway, 2006).

Reflexivity refers to the researcher’s ability to consciously and deliberately engage in self-examination in relation to the development of data collection and data analysis (Roulston, 2010), so that the attitudes and feelings of the researcher are recognised as influencing the process. A reflective diary was used to identify the reactions of the researcher to the data set, the values and attitudes that existed before data collection and those that emerged afterwards. The diary was used during thematic coding of the data set with the purpose of later becoming an important check on the emergence of research conclusions (Lysack, Luborsky, & Dillaway, 2006).

In this study, the reflective diary went further by influencing the development of the research process, as described in the following quote:

“I feel a bit concerned about carrying out the interviews myself. I would not be a neutral participant in the research process. Already my previous experience, professional philosophy and assumptions about the service are creating bias within the research process. I have desires for the project and its outcomes which are all wrapped up in my previous experience and assumptions. I would not be objective. I know all of the staff members, the people with autism whom they

work with, where they work, and I work alongside their management structures. They know me and my professional philosophy. I think I should use an interviewer from outside the service” (November, 2017).

3.7.2 Transferability

The goal of qualitative research is not to produce factual statements that can be generalised to other people or settings, but rather to deliver descriptive, context-relevant statements (Guba, 1981). In this way, transferability is the way in which qualitative research, such as this study, can be applicable or transferable to wider contexts while still preserving their own context-specific richness (Ravitch & Mittenfelner Carl, 2015). In order to achieve transferability, the researcher included detailed descriptions of the data itself and the context so that readers can make comparisons to other contexts having as much information as possible (Ravitch & Mittenfelner Carl, 2015).

3.7.3 Dependability

Dependability in qualitative research refers to the stability of the data. It ensures that the findings are consistent and could be repeated (Amankwaa, 2016). It demands that all stages of the study including data collection, analysis and arguments drawn from the data, be described in detail so that the reader knows it is answering the research question (Ravitch & Mittenfelner Carl, 2015). Therefore, the context of the population being sampled, along with a description of the study design, sampling process, the development of the interview guide, data analysis and emergence of themes have been described in detail in this thesis.

Another strategy used in this research study, was a code-recode procedure during data analysis. After initially coding the data set, the researcher waited for a period of two weeks before returning to the data and recoding to compare results (Krefting, 1991).

3.7.4 Confirmability

In this research project, confirmability was addressed through reflexivity of the researcher, as described above. Due to the nature of the study being undertaken, that of a MSc, the researcher did not have access to a research team to perform auditing to ensure neutrality of the study (Krefting, 1991). However, the researcher had regular

meetings and reflections with the research supervisor and fellow post graduate occupational therapy students throughout each phase of the study. This ensured that the researchers decision making at each stage of the research could be well understood and there was shared agreement that had others being carrying out the research in the same research context, the same conclusions would be drawn from the data set.

3.8 Ethical Considerations

Ethical approval for this research study was granted by the Research Ethics Committee, Faculty of Health Sciences, Trinity College, Dublin 2 in November 2017. Local ethical approval was granted by the autism service where the study took place, following ethical application, consultation and meeting with relevant management structures and the director of services.

Copies of both Ethical Approval Letters are included in Appendix A.

3.8.1 Ethics in recruitment

The researcher upheld ethical consideration throughout the recruitment stage of the research process, by ensuring that participants were sought on a voluntary basis only. The gatekeeper distributed a Letter of Invitation to Participate to all day service, residential and garden location sites within the service. Staff members then had an opportunity to decide themselves to approach the researcher to gain further information about the study. The researcher did not have any direct conversation with potential research participants about the research project, to avoid coercion.

3.8.2 Informed consent

The researcher gained informed written consent from each research participant prior to commencement of the data collection process (see Consent form in Appendix D). Once the researcher provided potential research participants with the participant information leaflet and interview guide, a period of at least seven days was given for consideration to participate in the study. The researcher then met with the research participants and were afforded an opportunity to ask questions and request clarification on any aspect of the study, prior to setting a date for interview. Once satisfied, a date for interview was

scheduled and participants signed a consent form before commencement of the interviews.

3.8.3 Confidentiality

After consent was gained to participate in the study, each participant received an identity number. The identity numbers were used during coding of the data gathered. With the intention of maintaining confidentiality, the participants were grouped into three groups:

- Day service staff
- Residential service staff
- Garden and maintenance staff

Only the research supervisor who completed the interviews had access to the key to connect the participant's names with the identity number. This information was stored separately to the anonymised data, with which the researcher had access. Participant names were not used on any data collected. The signed consent forms were kept separate from all other data.

Hardcopies of the anonymised data were stored in a locked cabinet, with which only the researcher and supervisor had access. The audio recordings of the interviews were kept in this cabinet, with the code stored separately. Audio recordings of the interviews were transcribed by the research supervisor, and any mention of the name of the service, staff or service user could be anonymized at this stage.

3.8.4 Debriefing

As discussed in the Participant Information Leaflet, it was not envisaged that any participant would experience any adverse risk or harm as a result of taking part in the research. However, any participant that expressed concerns were urged to discuss them in a debriefing session with their line manager within their location site. As all staff members and all levels of management were aware of the research study being carried out on site, this was deemed a natural protocol, if needed.

3.9 Critique of methodology

Using interviewing as a qualitative research method has both strengths and limitations. The interviewee may be unaware of certain facts and experiences being relevant to the

research question (Lysack, Luborsky, & Dillaway, 2006). To account for this, a detailed participant information leaflet was provided, along with the interview guide, which was provided to participants for reflection and an opportunity for in-depth thought, for at least one week before their interview date.

A lack of skill and training in interviewing can lead to poorly developed questions, inadequate probing and follow-up questions during interviews (Lysack, Luborsky, & Dillaway, 2006). The research supervisor who completed the interviews for this research study was a very experienced researcher, with many years of experience carrying out interviews within an occupational therapy context.

Using interviews as the sole method of data collection was deemed appropriate for this study as it allowed for a great volume of detailed data to be obtained about staff perspectives and experiences of supporting adults with autism to participate in daily life. No objective data on this issue was required to answer this research question (Lysack, Luborsky, & Dillaway, 2006).

Braun and Clarke (2006) outline common shortcomings that can occur during thematic analysis such as overlapping themes, failure to offer adequate examples from the data set during write up and failure to analyse data fully. The researcher ensured to familiarise herself with the data analysis technique and was mindful to avoid such pitfalls throughout the process.

3.9.1 The Academic-Practice Gap

Balas and Boren (2000) state that it takes 17 years for research evidence to benefit patient care, highlighting a disconnect between academia and practice. Fox (2003) suggests 'academic encirclement' as cause for this disconnect. Fox (2003) states that in academic circles, there is a culture which suggests that research ends once the paper has been published. He recommends that 'evidence-based practice' should be accompanied by 'practice-based evidence'. The researcher of the current study recognises this disconnect, and so chose to involve the practitioner, in this case, the support staff, in the generation of research and knowledge, as situated within their own unique context of an autism specific disability service setting. As the researcher is situated and working within the study site, the researcher will be able to feedback findings of the study to

management structures and support the implementation of recommendations without delay.

3.10 Conclusion

This chapter has outlined the aim of the study and provided a detailed description of the study design and justification for the approach taken. The research population and sampling methods were described, including a thorough description of the stages of data collection, data management and data analysis. Matters relating to the trustworthiness of the study were discussed, along with ethical considerations including consent and confidentiality. The following chapter provides a detailed description of the results of the study.

Chapter Four – Results

4 Results

4.1 Introduction

This chapter provides a presentation of the results of the eight staff interviews that took place in two sites, one was the occupational therapists office and the other was an office space in a community house. Interviewing was from December 2017 to end of January 2018. Around this time there was a change in the management and changes in the physical space of site locations. The interviews on average took 38 minutes to conduct, with the shortest being 24 minutes and the longest lasting one hour and 5 minutes.

An initial introduction to each participant is presented in Appendix E. Their three work site locations are described below. The five themes that emerged from the data set are described as a subjective interpretation of the data. The key words were highlighted within the text intuitively to aid the researcher in organising the data. Finally, a short summary of each theme is presented (Appendix C).

4.2 Work Site Locations

Participants come from three different work site locations. Each differs in context, roles and responsibilities and working hours.

Table 4: Staff Groupings

Staff Group	Description	Number of Participants (N=8)
1: Day Service Staff	Day Service and Outreach Day Service Staff	3
2: Residential Service Staff	Residential Service and Outreach Residential Staff	3
3: Garden Staff	Horticulture staff, Garden activity staff	2

4.2.1 The Garden

Two participants work in the location of the garden which is situated on the same site as a day centre, a number of single occupancy apartments and three group homes. The garden

consists of work sheds, a polytunnel, vegetable plots and a large lawn with a path around the perimeter lined with flower beds. There are approximately five Community Employment staff who work in the garden and within maintenance. One of the participants came from this group of workers, who's main responsibilities are to maintain the grounds on the site and complete maintenance jobs in the various houses and buildings. This participant works only in the garden, facilitating service users to engage in garden tasks and activities alongside him.

The second garden participant is officially part of the day centre staff team but for the majority of her time, uses her horticultural background in the garden with one particular service user.

4.2.2 Residential and Outreach Residential Services

Two residential staff participants work in two different residential group homes. There are up to five people with autism living together in each group home. These group homes have staff present 24 hours per day, with staff sleeping at night time. The majority of service users do not attend a day service. The staff are required to provide a day service to the service users, while also supporting the person's personal care and completing housekeeping, cooking and record keeping tasks. The third residential staff participant works within the Outreach Residential Service, with service users who received individual funding and live in their own home, usually in rented houses in the community. Staff can be present on a 24hour basis or this can be reduced depending on the needs and wishes of the person with autism. This participant holds the same responsibilities as other residential staff, relating to the cooking, cleaning and report writing.

4.2.3 Day and Outreach Day Services

There were three day service participants, working in three different day service settings. One day service location was in transition from a large day centre (congregated setting) to smaller individual 'hubs'. This day centre is on the same site as the garden, three residential group homes and a number of single occupancy apartments. The staff to person ratio is six to three. Service users arrive before or at 9am and go home around 4pm.

The second day service location, termed “Outreach”, differs in that the service is located in a rented house in the community. Approximately three service users attend each house during the day between the hours of 9am and 5pm. The staffing ratio is one to one unless staff or service users choose to do groupwork. The staff support service users to work on goals and access the community from this base. Staff report a responsibility to engage service users in household tasks and support them to learn these skills. Cleaning and report writing are completed at the end of the day when service users return home.

The third day service location, termed the “Outreach Transition” service is located in the community, where staff have a base (a rented house) in the community, mostly consisting of office space, with a kitchen, sitting room and garden space for use with service users. This staff team work with adults living in the community, who require only a number of hours support during the week, to work on specific goals. Staff meet the person in their own home, in the community or in the base house.

Table 5: Experience Working with Adults with Autism

Staff Group	Least Experience	Average Experience	Most Experience
Garden Staff (N=2)	2 years	12.5 years	23 years
Residential Service Staff (N=3)	3.5	3.8 years	5 years
Day Service Staff (N=3) <i>No data from interview 8</i>	1.5 years	3.75 years	6 years

4.3 Development of Themes

Braun and Clarke's (2006) thematic analysis was used to analyse the data gathered from the interviews, as described in detail in Section 3.6. The results of the interviews are presented and organised under the following five themes, as shown in Figure 4.

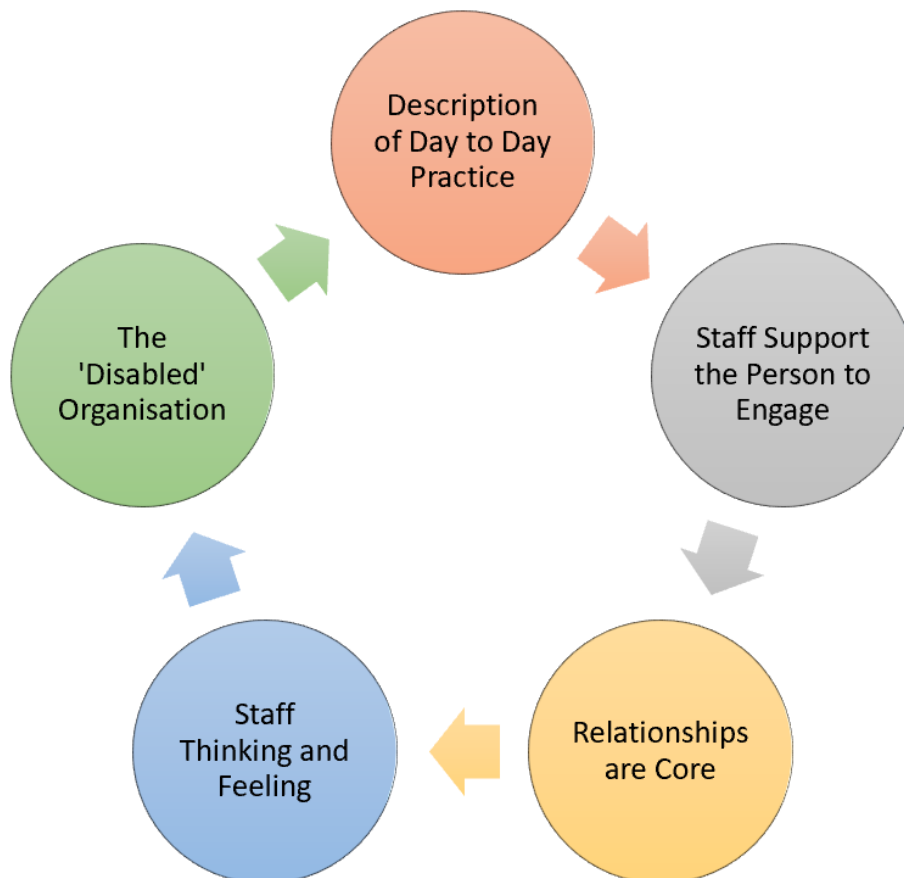


Figure 4: Major Themes from Study

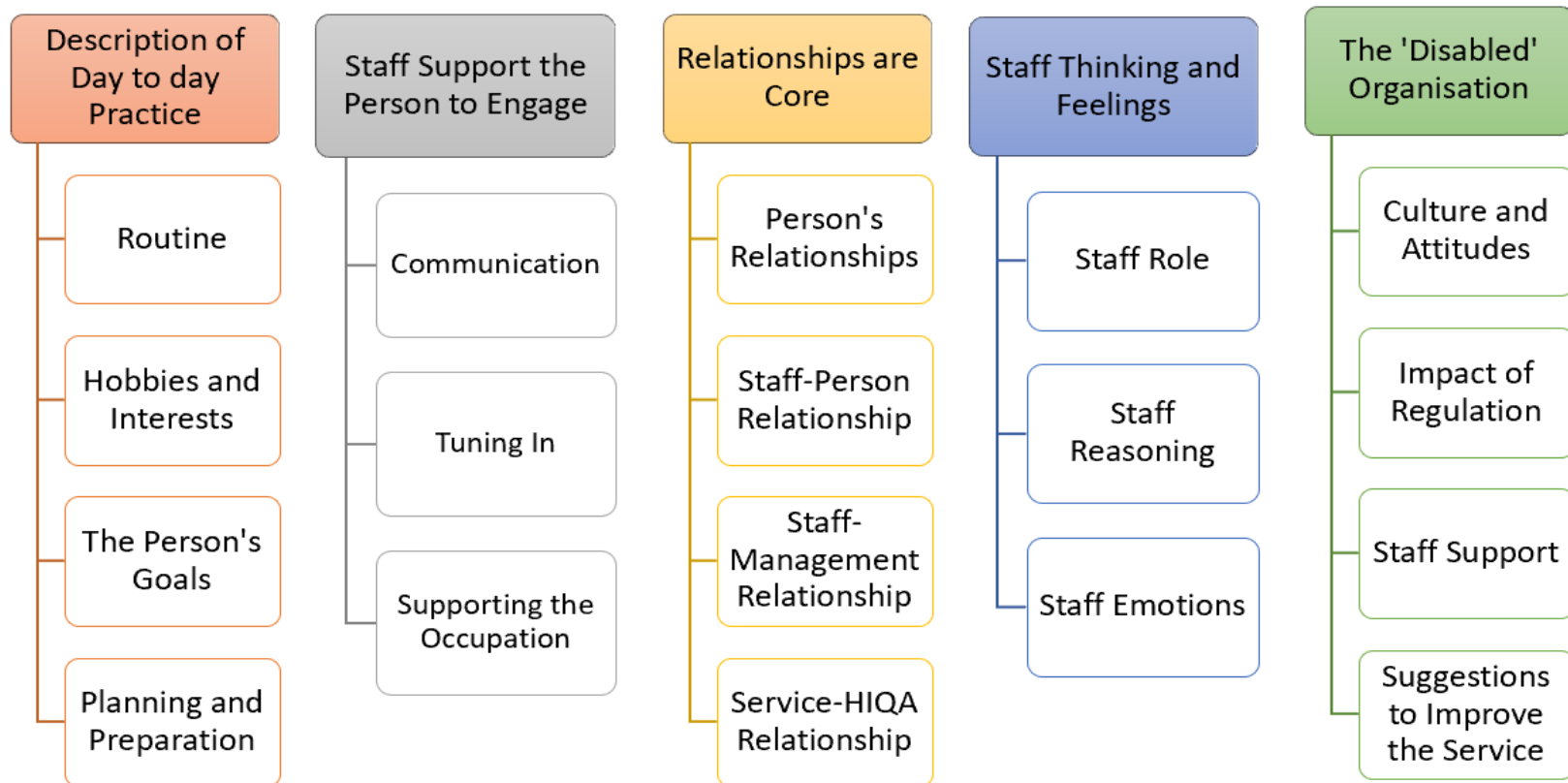


Figure 5: Depiction of Themes and Sub-themes

4.4 Theme 1: Description of Day to Day Practice – “The What”

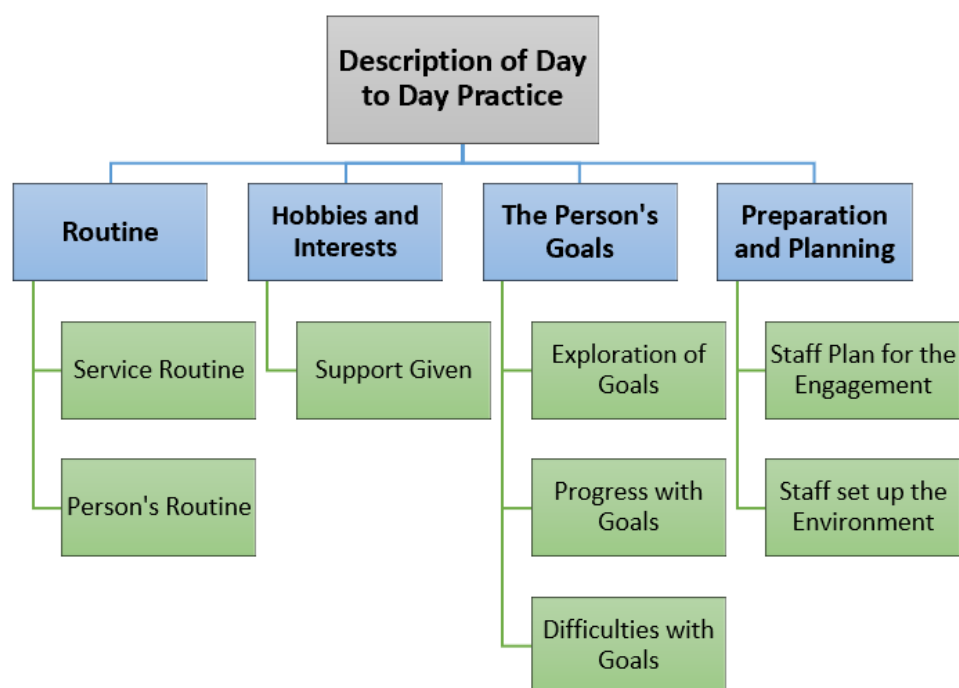


Figure 6: Theme 1 and Sub-themes

The first theme in this analysis is “Description of Day to Day Practice” and provides accounts of staff describing the day to day work of supporting people with autism within the service. Two sub-sections discuss the routine of the service and the person’s routine. The second sub-theme describes the type of support given and also the difficulties residential staff face when supporting people’s hobbies and interests. The third sub-theme contains three sections, describing the exploration of goals, progress with goals and difficulties experienced by staff when working on the person’s goals. The fourth sub-theme details how staff plan for the engagement and set up the environment.

4.4.1 Routine

The number of people supported at any one time varied among participants. Two participants always work one to one, three participants work through a mix of individual and group sessions, and three participants always work with more than one person (detailed further in Appendix E).

Table 6: Number of people supported by staff at one time

Always 1:1 Sessions	Mix of sessions	Always working with more than one person
x1 Residential participant x1 Garden participant	x1 Garden participant x2 Day service participants	x2 Residential participants x1 Day service participant

4.4.1.1 Service Routine

The three participants who always work with more than one person described negatives of this routine impacting on providing a person-centred service. One residential participant describes the conflict that may arise between service users, *“often, five different people sharing the same staff becomes a conflict of, I wanna do this, I wanna do this”*.

This is in contrast to the positive way the five other participants with one to one sessions, and those who have a mix of sessions, describe their service’s routine, *“We are lucky... We have the option to do both”*. The routine of the service provided by these participants, seems to be driven by the person’s choices and goals. One day service participant described how she structures the service’s routine to support the person to develop planning and organisation skills,

“We just felt like he didn’t really have a concept of time or routine... We really felt like by me showing up to his house at a certain time that doesn’t give him any of those skills to actually have a routine then later if he wants to do other things, he ends up late or he doesn’t know the bus to get... Trying to support each step of that. Some of that you actually need to have a session before the session: ‘OK what time are you going to leave your house and what time are you going to have breakfast and what bus are you going to get. And where are you going to meet them?’ So, I suppose that’s kind of the change now in routine and having more control over time”.

Four participants reported conflicting responsibilities within the routine that have an impact on the person’s day, three of whom were working within residential services. They described other tasks that needed to be done, *“then you come in and something has happened. Somebody needs a prescription somewhere, you need to bring somebody to*

the doctor, you need to do this and do that". He describes other household tasks, paperwork, medical and health and safety tasks, that can take up lot of time;

"All of a sudden, we're being told... 'You have to buy particular cleaning gear. You can't buy Flash, you have to buy Tesco. You can't buy Tesco, you have to buy, such and such'... And, as well as buying that, you have to get the data information... So, I'm on the shift one night with this, with the poor [staff]...And, [they're] going around and [they're] saying, 'no, no, no, X bought those Tesco Flash cleaners... I've got to get the data sheets for them. I have to get the data sheets for them, we don't have the data sheets.' And I said, 'what?'... So, I said, 'ok can we go, let's go and Google it and have a look at the data sheets.' Couldn't get anything... I said, 'You go back and tell them to get that guy, or the health and safety committee, to give us a list of products we can buy and the data sheets with them... And then, all you have to do is implement it".

Staff's responsibility to complete these tasks mean that *"all the lovely stuff of supporting them in goals and activities and tasks gets put on hold"*.

The remaining four participants, three working in day services and one working in the garden report their sole responsibility within the routine as the person's engagement. One participant describes how they leave their household management tasks until the end of the day so that the person can start their day,

"We're gonna go out straight away we're not gonna sit around and kinda just wait or like if you have to do up the money. I'll just be like right, I'll leave that till I get back, my main priority then would be, to let's get the day going".

Three participants discussed how a change in the service's routine can benefit the person. One residential staff discussed how their team has come under new management and their work is being looked at differently, *"There's going to be a change in rosters and it's going to whittle it down to maybe 5 people seeing him throughout the week"* in order to provide the person with structure and continuity. Another day service participant describes how they structure the service so that their sessions with the person are meaningful,

"I suppose things have changed a good bit recently, in terms of we used to kind of give out people's hours or their sessions and just show up to their house at that time. That was kind of how the service was set up... We're really trying to get

away from that... we ask him to plan the sessions in advance and now we don't really go to his house unless there's a reason".

The participant working in the garden, reflects on a time when her routine involved working with a group in the garden, *"I was part of the overall day centre. And, there would have been, we all met, we all were a big group and there was a list made, and I would be down with gardening with two people. So, that was, I'd go gardening with that group"*. Now there is an organisational decision and the participant is concerned that she may *"end up"* working back inside the day service, not in the garden.

4.4.1.2 Person's Routine

There was a difference among the participants in how they discussed the person's routine. The two residential participants working within a group home discussed how this needs to fit in with the wider routine of the house.

"So, for example, there's one guy over there at the moment and he's in his fifties, and eh you know he doesn't really want for much anymore, and that's not putting him down, he likes his quiet life. And, ehm, all he ever wants is... maybe have a lie in in the morning, get up at lunch time or a little bit before lunch time, have a shower, come down have his lunch... and then ehm maybe in the evening, because he's never he doesn't want to get up, you see, in the evening time then he likes to have his dinner and he loves to say 'will we go for, can we go for a cup of tea and a muffin?.. Can't do it'".

The participant describes that this is due to safeguarding protocols in the house regarding another resident's behaviour. The participant expresses frustration that management do not seem to value the person's own routine, *"Now, and then you'll get the answer back, 'Well, bring him out in the morning time or in the afternoon'. No... That's not what he wants... And it's not his, it's not, do you know?"*.

Another residential participant echoes this frustration about how the routine of the house and the other residents may impact on a person's life,

"You know, you don't know what kind of frustrations are going on, and they didn't choose each other as housemates, you know. They were kind of put together and hopefully they won't kill each other, kind of thing. That's generally how it is in these places".

This is in contrast to how other participants talk about the person's routine, where the focus is on the person's plan, what they want to do, what options they have and how they can change their plan if they so wish.

One day service participant uses the routine to help the person learn planning and organisation skills to be *"better at structuring their own routines"*. Another residential participant described using the person's routine as a way to keep the person regulated,

"I'll often go out with a couple of the lads, go for a walk, where there's not a lot of distractions, a beach, or yeah somewhere in a park where there aren't you know lots of cafés or shops... Ehm, so there are patterns of what we do to get the guys out of the house and help them feel more relaxed and there are clinical plans around some of it so that they use up energy and sleep better so they're not like relying on medication for sleep".

Four participants discussed change within the person's routine. One participant discussed how facilitating the person to change their routine can present opportunities for engagement,

"We try and support them with their routine or even changing the routine, you know. But ehm, most of them would be quite flexible, actually. And I think it's really interesting, there is a service user... in the past we thought that he would be really you know, ehm he needs routine, he needs his schedule and stuff like that. But, since he comes over here, at least once or twice a week, we realise that actually he's not that stuck with his routine, he can be totally flexible... And eh, we can try so many more things here with him than in the other house where we were, you know, really stuck. It's is a new environment for him, new people around and he's more, flexible".

Two other participants discussed enforced change in the person's routine, related to organisational decisions such as changes in day service provision, where people's day service was moved from day centres to their residential houses (discussed in Section 4.7.2.4). Another participant who has been working with a person in the garden for years, describes the possibility of the person losing his role as worker, and relationships with his co-workers in the garden due to an upcoming decision, *"Things are going to change... His house is going 24 hours, probably at the end of the month, so I won't be working with him anymore"*.

4.4.2 Hobbies and Interests

4.4.2.1 Support Given

Throughout the interviews, all participants discussed what they do to support the persons hobbies and interests and gave examples.

“Say one of our service users for a while was going to Dog’s Trust, to walk some dogs. And that was because he mentions his dogs name every so often and does appear to enjoy it. So, his keyworker decided this might be a nice thing for him to do, because he likes to go out and go for walks anyway, so why not walk a dog. So, you’re trying to think creatively for service users”.

Similarly, another participant described how they used a person’s interest in healthy eating to engage them in a community group as a social activity for the person,

“One of our service users wanted to lose weight, and ehm, he was going through kind of healthy eating. So, I suggested Slimming World. And I kind of gave him the brief map of to what slimming world was, and we went through it we sat down together, we looked at it the computer. Ehm, to see would he be interested... so I was kind of explaining what way the group would be, and that we’d listen to others and that it’s not a diet, it’s a food optimising. And so, this was completely new to him. And ehm, he was really interested in doing it. Ehm, so he went with it and he absolutely loves it now”.

Another participant describes how she uses horticulture *“every day in order to enhance people’s lives. And to get the best out of them”*. An indication of the benefit of this engagement for the person is seen when the participant discusses how the person stacks items when stressed but does not stack when working in the garden. Similarly, one residential participant describes the buzz they get from people surprising themselves with what they can do,

“The biggest kick I can get in the job is when somebody does something they thought was impossible”.

Six participants discussed how they explore the person’s interests. Each participant does this differently and it seems to depend on the person. For example, one participant working within day service, would do it,

“Either through individual sessions or groups, so... You might have one of those conversations of, you know, is there anything you’re interested in doing... What I’ve kind of found recently is using something like an interest checklist is helpful... I’ve found one particular person you could ask him that and he’ll just say ‘Oh I don’t know there’s nothing really I can think of. And then if you did the interest checklist there was 10 to 15 things that actually he really wanted to try and get involved in”.

Similarly, another day service participant uses a ‘Voice and Choice’ forum, where the person has a chance to say how their schedule is going and if there is anything they would like to change. One garden participant does this through observation. Two participants discussed the benefits of exploring interests in a group.

Staff support engagement in hobbies and interests by setting up the task for the person or group, *“I set up things... One or two like to do painting so I organise stuff for them to paint... One or two lads yano they pot up flowers so they hang baskets in there. During the winter I’m making up signs”.* Three participants discussed helping people to try new things, to see what people are interested, or to just break their routine of doing the same thing all the time,

“So, that, like, helping people to kind of push their boundaries, then you find out what they do like and what they don’t like”.

“Our lads would have, ehm. Like, one service user would be very, he would know exactly what he wants. You know, he would be very adamant of, so trying to kind of bring in new activities into his schedule. And to try to open his mind up as well, because I think as well with autism, it’s very, there’s a very routine. And, there’s kind of, they need to get those kinds of choices in to build on their interests”.

The key to this support appears to be about how well the person is known, as described by six of the eight participants,

“I suppose we’re lucky in our service that we know them quite well, so we might have this exploring every couple of weeks or months. It’s not so much a first interaction. I suppose from getting to know them you can kind of come up with your own suggestions as well because sometimes they might not think of it off the top of their heads”.

All three residential participants described difficulties,

“Now you see we have five service users. Ehm, there are two people working with them. That’s ok. Yes, the support end of the job as in looking after them, from advocacy, to their health care, to all between medical and social... Where I work, we have a plan, for each day where we try to accommodate every service user to the best of our resources and abilities”.

In addition, the residential participant working with only one person at a time, described how the people they work with don’t actually want support with their hobbies and interests,

“So, as regards hobbies, they’re kind of self-sufficient. They’re kind of doing their own thing... They would generally do their own thing... Like one of the guys would be into a lot of IT stuff, which I wouldn’t really have much, like, they’d be nearly guiding you... I wouldn’t really be up to speed on that sort of stuff you know. Like some of the guys then they’re in gyms, yeah, they go independently”.

4.4.3 The Person’s Goals

4.4.3.1 Exploration of Goals

Seven participants spoke about exploring and or supporting the person with their personal goals, all in different ways. Participants from all groupings describe chatting with the person about what they wanted to do, experience or achieve; *“I had a little talk with him last week, and I have his goals and all down here”*. Two participants describe with non-verbal people, they use observation to infer what the person might want to do. One residential participant explained that they *“would help them develop what they’d either shown they had been interested in by their behaviour or, if possible, they can ask”*. This same participant describes how he offers experiences and opportunities for people to push their boundaries, describing taking some residents on a cliff walk. Another participant describes how he built on a person’s expression of interest in working on a building site, and invited him to work with him in the garden,

“On a Wednesday I have two fellas, two lads, down the garden and how that started I was asked, one fella expressed his desire... to work in a building doing labour. I was asked would I be able to, would I have any idea. I gave it a bit of thought and came back and said there is a lot of digging to be done, getting ready for planting for next year. He comes down now”.

Two participants describe more involvement in the exploration and identification of a person's goals. A day service participant states that the person chooses the goals, and she adds the steps to it so that he can achieve it, stating that the development of goals is *"a mixture"*. One participant describes that the goal setting process can take time,

"I suppose we're lucky that we see people over such a long period of time that you can, you have the freedom and you have long amounts of time to explore things and discuss things with them and then sometimes you come full circle and come back around".

One residential participant echoes this, discussing the weekly key worker meetings, *"where weekly we're meant to sit down with your... take weekly out of it... Weekly? What? What are you talking about?"*.

4.4.3.2 Progress with Goals

Many participants described how they practice goals with a person, from practising the skill of baking in the persons home, to driving a ride on lawn mower in the garden, to practising professional behaviour for working life.

"He had an interview for, with a job officer, and the whole thing you know like, he was late, he was really inappropriate, and all this kind of thing happened. And while, his goals before that, weren't exactly, 'being professional' and 'being on time', from that it came, well actually, that's going to be your main barrier to employment if you can't get past that interview stage you can't get there. Ehm, then actually that's what we really need to work on, and can we do that through everything, even if we're just meeting up for a walk, still it's, it's not in your house, it's we're meeting at the place that we're meeting, and if you're not there in ten or fifteen minutes I'm going to leave. Because that's what would happen in an interview, or any kind of appointment".

Two participants state how progress can be slow, with one day service participant describing how they are there to support the person to develop skills, but,

"It's hard it's so slow, though. So, that's what's difficult because you know, they need time. So, my goal would be that yeah like you know, help them in their future but at the same time yeah, it's really, really slow".

Another residential participant echoes this, saying *"you do want them to develop, but they want to develop in their own way"*. One garden participant describes how they have a

goal for the person that their transition from the service to home will get easier with time. She describes that they have been working on it for years and just recently they have seen progress,

“Ehm, in the past three months... We’ve seen a huge change in him which is really enormous. Ehm, he actually thanked me for bringing him home recently. This is enormous like, and today he said to me ‘will you bring me home next time?’”.

Participants describe the joy when they have success with a person and how they notice this success. One day service participant describes how the person has been supported to learn how to do his tasks and can now do them independently,

“Now before like he didn’t know to take the basket, to get your groceries, so once that was kind of implemented like he’s, he’s really good at following instructions, so he will then get the basket and fill up all his groceries and pay for it. And then he’ll walk from the Aldi... to... where the Slimming World group is. So, he’ll walk there and he’s, oh like he’s fully able to”.

Another participant describes how the person has changed and attributes this change to how he has been supported over the years,

“I really do feel we’ve given him a really good chance. And we’ve given him a lot of stability. Like, he’s gone from breaking doors and punching windows and hitting people and causing injury to people, to being, [A worker]. Yeah, and he identifies as a worker... And a valuable part, you know”.

She is noticing the person is still developing and provides many examples, one from his father’s reports,

“He was home for a full week, while the Dad had the option, if there was any problem, bring him home, bring him back, ehm and he said... I think he actually used the word ‘enjoyed’ his time. Yeah. ‘Enjoyed his time with X”.

Two participants describe how they receive feedback from the person, with one describing how they ask the person to self-rate their performance,

“So, I would have said to him like how do you feel out of ten how good do you think you are at doing this, like how well are you able to do it on your own? And he said 7 and he’d like to do it once or twice more”.

4.4.3.3 Difficulties with Goals

One participant describes difficulties with the person not wanting to set and achieve goals,

"You would try, what I would try to do is do it in a really casual manner like, because the lads generally don't want to be kind of, you know it's their house as well, so I respect that, but they don't, they're not really into sitting down and doing goals and objectives and kind of what they want from their lives in a kind of, in a normal kind of manner".

A day service participant describes a tension between staff promoting the person's independence and the person's lack of activity and responsibility in their family homes,

"What's difficult sometimes, is OK they are adults, but they live at home. Which, is not a problem. But they do live at home. So, the influence of the family is quite a big thing... I find, that that part is quite challenging, sometimes... We do something here, and then they go home, and they don't really do anything at home. Because everything is done for them. So, we are trying to achieve their independence, but at home it's totally opposite".

All residential participants described difficulties with supporting a person's goals due to staffing ratios, with two attributing it to staff being *"thinly spread"*. Another discusses how one service user might see ten to twelve different staff during the course of one week.

Two day service participants describe staffing issues as a barrier. One explains that they do not have enough staff, while another refers to continuity as a barrier for the person,

"I suppose it's different in our service because the next session might actually not be with me it'll be with a different staff member, so that can make it a bit harder to do that progression piece because you have to pass that onto them, what they're working on and it's not as natural sometimes. So, I suppose the recipe is what stays the same even if the staff members changing and just trying to stick to following the instructions and prompting to look at the instructions. And trying to I suppose approach it in the same way but you don't know with different staff do some people help a bit more or do some people leave it more up to them, that's where the challenge can be sometimes like that, with the following on session after session".

4.4.4 Preparation and Planning

4.4.4.1 Staff Plan for the Engagement

Three day service and one garden participant described how they plan and prepare for the persons engagement. One described how she supports the person to plan for themselves, using a weekly schedule.

"I kind of had the idea to ask him to draw a character of each goal he has or each cleaning activity. So, then he had up there you know, the 'Evil Character', planning and organising his next crime, and... one of his other characters sweeping the floor... And it did, like, he still doesn't use the thing all the time, but... Stick them up on the days that you might want to do that, and I think having it kind of visual... Having it that some things stay there the same, you know that laundry is the same every week".

She describes how staff also plan for the person, by liaising with each other and using the roster to remind staff what tasks need to be done to support him to engage.

"I suppose that's why we kind of have the key worker... So, making sure, ok could you remind him about that, has he called your man, do we need to put it in the roster... And then at meetings, you know I'd be the one to say, you know, this is what we're kind of working on this month".

Another day service participant, describes how the person has a goal to travel to London, but staff need to support the person to plan,

"So, like I planned it for him, like the steps that like, you know ehm the passport, and then the step by step there was a plan that first you go to the post office for the form. And then he did that. So, but I did write down the steps and I explained, and I just give him the sheet and you know like today you need to do this. And then he did everything independently, he just needed to know how to do it".

One day service participant uses text as a method of planning with the person, "We have... A work phone so we're lucky that we can send someone a text if you're planning a session for the next week or few days' time and talk about something with them or suggest an idea over text". She also describes planning in how she can support the person to self-advocate in meetings with his family by providing written supports for the meeting and an opportunity for him to provide feedback through writing. One garden participant also describes how she plans for the persons communication with the next staff on shift

with him. She will put as much information as possible in his daily report so that the next staff can form meaningful conversation with him,

"You know, and then when you're writing your report you're trying to add in as much detail so that if X said 'my friend', you might be able to say 'oh he met Mr. Y yesterday', because he may not be able to say who, the name".

She describes how she prepares the person for his transition from work to home. The participant and a maintenance staff will begin to mention the persons family throughout the day, to prepare him for going home, *"We'd start mentioning Dad earlier in the day. We'd start mentioning family, and just slowly infiltrating all the conversation in".*

One day service participant describes how a person stumbled on the bus and how she supported the person to prepare for the next time they get on the bus with shopping bags.

"We were getting off the bus, I was like 'it's ok, lets breathe, we'll get off the bus', and he did apologise though to the bus driver, which was really good. Ehm, and then just kind of have deep breaths, and then what way we should maybe carry, or hold the pole, instead of kind of just balancing, and maybe we could move the bag up around where our wrist is, or we could put it over where there's like a little basket kind of to put it in to".

Another describes how she prepares for the engagement before the person arrives to day service.

"I just try to think, what's going to happen on that day and if something needs to be prepared, I can prepare it for them before they come in... I would prepare I dunno like sheets for him. Or, if I know that, that his goal is to work on... money management, or relationships. I would try to think of exercises or ideas where we can actually practice".

One participant describes planning that is done on a day to day basis, with staff contacting the person on the day to see what they want to do. There is no reference to goals that are worked on and planned for, *"with the guys in the house, it is planning, eh, day to day, yeah".*

"It depends, yeah I mean the guys who are out in the community living on their own, generally you'd give them a text or a call earlier on that day, 'are you still on to meet up today?', or whatever, 'do you, is there anything you fancy doing?', or

'is there anything planned to do?', and they would generally get back, you know. Eh, and it's usually quite functional stuff, you know".

4.4.4.2 Staff set up the Environment

Two garden participants, one residential participant and one day service participant describe how they set up the environment for the persons engagement. One garden participant describes how she would use music to set up the environment, *"A certain sound track I'd often play 'Take That' in the mornings. So, that sets up a certain ambience, a certain, you know just feel to the day"*. This participant explains how the person stacks DVD's in his bedroom, but that staff don't allow him to stack anywhere else in the house, *"The rest of his apartment is sparse. They don't allow him have anything else, anywhere. Because there's that encroachment then, you know, so his room is busy, but everywhere else is very calm"*. Interestingly, she states that the person does not stack in the garden, but they have provided him with his own space to have things, *"He would hoard a little bit in the garden. He has his office. We gave him his own office. So, he would often put things in there"*.

One day service participant describes how a change in the environment or routine can support the persons engagement, as described in section 4.4.1.2. One garden participant describes how he sets up tasks for the person to engage with in the Men's Shed while a day service participant describes her use of materials when supporting a person to engage in learning how to bake buns.

"When we are cooking, you know, instead of asking me a question, look at the box, what does the box say, what's the first step. Did you forget something? ... Look at the box instead of looking at me. Because, that's going to be there when you do it next time".

4.5 Theme 2: Staff support the person to engage – “The How”

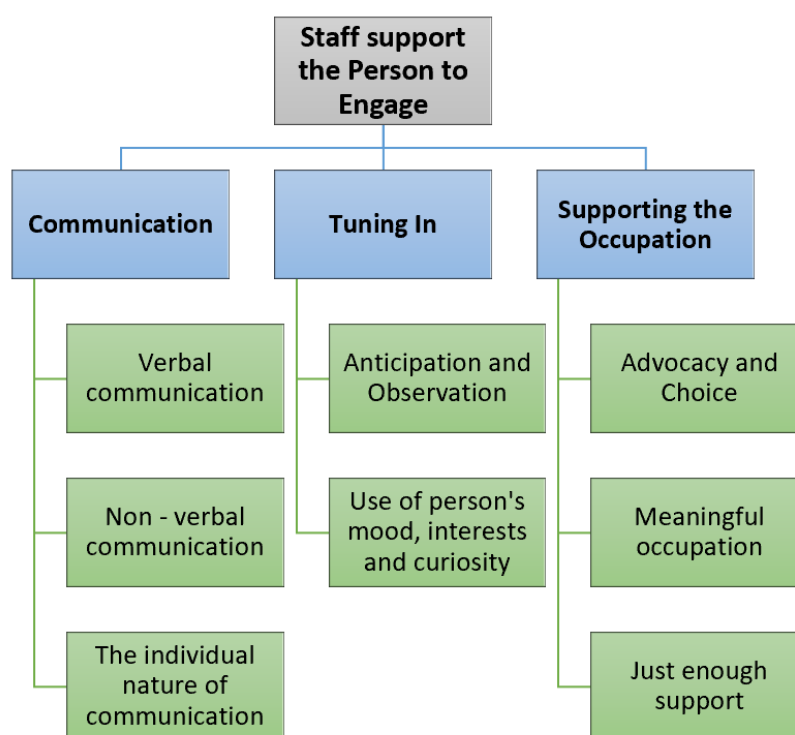


Figure 7: Theme 2 and Sub-themes

The second theme in the analysis is named “Staff support the person to engage”. The first sub-theme is ‘Communication’ and describes verbal and non-verbal ways staff communicate with the person, and the individual nature of communication. The second sub-theme deals with staff ‘Tuning in’ and includes a description of how staff use anticipation and observation, and work with the person’s mood, interests and curiosity in order to tune into the person. The third sub-theme is titled ‘Supporting the occupation’ and deals with advocacy and choice, meaningful occupation and how staff provide just enough support to the person.

4.5.1 Communication

4.5.1.1 Verbal communication

All participants describe people whom they work with who have some level of verbal ability. A number of participants explained how people who are verbal can be supported in communication, stating that they need to be mindful of how the person is processing information,

"Yea well I suppose everyone we work with is verbal so they can tell you what they want to do. But there are different ways still to support it... and definitely I think even though they are verbal, you can over, I think, expect them to know, to hear everything you're saying and to process it".

One day service participant describes how they support people to communicate more effectively and meaningfully through writing or text messages.

"Like some people we support would actually communicate better by text or email rather than asking things in person. You know when they have a bit of time to think about it and then reply to your text".

A garden participant describes how he allows people time to process his question, and listens for the answer stating that he has *"to dig for it right, took me now four or five minutes to dig for it"*.

Three participants discussed how sometimes, less talk is better for the person, sometimes people don't want to talk at all and sometimes you need *"to speak maybe a bit slower"* in order for people to process what you are saying.

"Verbal communication with him, a lot of the time less is more. So, the less words you use, the better... You know, ehm. Ah, he'd say to you 'chat, too much'. You know, and if there's other staff around he'd give out about us chatting too much".

One participant describes how she repeats back what the person has said, *"echoing what he's just said"*. One day service participant describes how she listens and observes the persons emotions and will then provide emotional support in a chat, where she is *"listening"*.

One residential participant describes how a person they work with has echolalia,

"He speaks a lot but much of it is echolalia, and he will often say, 'yes' when he means 'no'. And, sometimes, he'll repeat what you say, so you have to be careful not to ask leading questions".

If the participant did ask a leading question, *"when you see him becoming confused, you have to, instead of listening for the word he says, you have to listen to how he says it"*.

This participant provides an example of how he listens for the emotion in the persons answer.

"I was on the bus earlier on, and he became, he said he didn't want to go out. And he always wants to go out. As most of the guys do... But he was saying no, and I was like, ok, this is unusual. So, I just pulled over, and I just said the word 'drive',

and then he went, 'drive'. And he felt relieved. I could hear the relief in his voice, he said 'drive', so I was like Ok, he isn't asking to go back, he just heard what I said and repeated it back".

He explains his rationale for communicating with the person in this way,

"In that instance... It was trying to see if the normal prompt for him to go out, ehm, lead to an anxious reply or a relaxed reply. And it was visibly more relaxed... So, when you're communicating, you're looking for emotion. Because you're trying to read how somebody's feeling, and even the people who are verbal, and can communicate well... Sometimes may be led into saying something. So, you have to be very careful about how you phrase a question".

One garden participant describes the efforts that have been made in the past to improve a person's verbal abilities, where every phrase the person said was recorded and noticed as progress in communication.

"His communication... definitely has improved over the past while. Ehm, for a while they were recording everything he said. All the phrases he said. You know, so that kind of, we have that book there to look back on, to see. And again, [one staff] would have put a lot of work into that".

4.5.1.2 Non-verbal Communication

Four participants refer throughout their interviews to communicating with non-verbal people or communicating with people in a non-verbal way.

The day service participant describes that *"we would use visuals"* to communicate with some people. One garden participant describes how he uses body language to read people as they walk in the door of the Men's Shed, *"The lads that I do be with on a Monday nearly tell me the way they walk in the door, where they are. You can have a pretty good idea alright"*. He uses expressions to communicate with people, by observing their face and doing their face back, *"I use a lot of expressions. I show a sad face. Yea. And they'll pick up on that... and... If they're happy, then they smile with me, laugh and joke with them"*.

Another garden participant describes how she communicates with the person through modelling, because they don't like too much talking or demands being made of him, *"You're all the time mimicking what you would like X to do. You know. So, if I, you know*

say it's cold. And I'll mimic putting on my coat. Ehm, then he might do it". Another participant echo this, explaining that a person he works with does not like demands being made of him, and he elicits choice from him by reading his emotions.

"When we're out, he doesn't like demands being made of him, so I'll tell him what I think he wants to order, I'll say I'm going to order this, and if he doesn't give me any response I know it's ok... But, sometimes he might shake his head if he strongly doesn't want something. And, at that point I have to very quickly go, ok this. And, he'll relax and that's ok. Ehm, otherwise he might get caught up, and he gets into physical loops and mental loops".

He also describes how he observes the person during an activity to read if they are still wanting to do the activity. He shows an awareness that people might say yes to doing something initially, but they may change their mind during the activity. He describes being out cliff walking with the person for the first time and how he knew that the person wanted to turn back,

"I think that, he was looking at the steps. He had gone through a few and he had stopped and looked at them, and I asked him are we going to turn back now? And he turned back... Ehm, and actually that was the second time I asked him. The first time he kept walking".

4.5.1.3 The Individual Nature of Communication

There is acknowledgment among participants that each person is different, and there is no standard way of communicating.

"There can't be a general approach, because... One person can speak and articulate what [they] want, one can speak but won't generally speak much, because he finds it difficult to physically speak. Ehm, and one has four words that I know about, including hi and bye".

He describes that every day is different, perhaps depending on the communication needs of the people that day, *"There is a lot of talking people through things, and redirecting people... So, sometimes I do talk a lot and sometimes I don't. It's a mix. There's really, ehm, there's no standard hour per day".* The day service participant describes how she communicates with people and concludes,

"It depends... So, my approach would be to get to know the person first, spend time with the person, have like you know, have ideas what could work... But anyway, it's up to the person and it's really individualised, I guess".

There is an acknowledgment among participants, that the person is thinking and can make choices, and there is intent to find out what people are thinking and choosing.

“There’s no way for me to really get inside a service user’s head... There’s no way, I can understand from my point of view, and I can try and understand from their point of view, but I’ll never understand completely what’s going through their head”.

This participant describes how he views challenging behaviour as a method of communication.

“You get to accept that every so often, a few plates will get broken. It’s a matter of communication. So, I’ll approach somebody smashing stuff in a café as, OK, immediately we get out, make sure everyone’s safe. But, it’s a form of communication. Sometimes it’s for an underlying reason, sometimes it’s just purely impatience because they’re waiting for somebody, another service user to do something. And, so, often, five different people sharing the same staff becomes a conflict of, I wanna do this, I wanna do this. The fastest way out of a café is to start smashing it up. And that’s the simple communication”.

One garden participant tells a story of planting flowers in the company of a person with autism. He describes how he learned that the person appreciates flowers, but states that this person might not actually be able to articulate this in the same way someone else would.

“He was up at the front door and was planting flowers and there was old roller-skates right. And I picked up a roller-skate and I put a new flower into it and he went ‘no no no leave that alone, leave that alone’. Right. So, I explained to him what I was doing. I didn’t hold the thing there and explain I’m going to take that out and put that in. When I was talking to him, I was doing it I was explaining it with me actions”.

He explains that the person might never say, ‘I like those flowers in the roller skates’, but by taking them away, he reacted negatively and relaxed when the participant showed him that he was replacing the flower.

One garden participant describes how she has to interpret what the person means by what he says, stating that certain words mean different things,

“You’re all the time thinking of words that he associates with. You know, later, can mean just not now. You know, tomorrow, or yesterday could mean anything, in the past. Ehm, he sometimes talks about being sick, but that’s a form of communication, ‘me back is sore’. Or, ‘I’ve a heavy cold’, ‘a cold’, and you know he’s, it’s just a conversation piece that he’s, he is expressing some kind of need, but it’s not necessarily a cold”.

One residential participant states that the person “doesn’t answer directly really, and you just have to let it come and go”. Another garden participant states, “Now he’s very, limited speech, ehm, can’t always think of the right word for things. So, your kind of flowing with him and figuring out what do I think he’s trying to say”. Her method of communicating with the person does not fit clearly into verbal and non-verbal communication, but rather it shows the individuality of the person, and the importance of the relationship and knowing the person. She describes how she uses modelling, as described earlier, and how she cannot directly tell him to do something,

“Now, this is a funny story... The bathroom here, is horrible. It’s the one down here that we use, cause he’s not allowed go beyond the green gate. So, I have to keep that locked. So, I do have to say to him, ‘don’t lock me in. You’re not to lock me in the bathroom’. So, he locks me in the bathroom. He does. Right. And, I’d be saying ‘I hope you didn’t lock that door’. This is while I’m going to the bathroom, ‘I hope you didn’t lock that door. If you locked that door!’. But he’s outside giggling... So, then I know where he is. He’s laughing. So, then... I go really silent, and he thinks I’ve gone. And he opens the door. You know”.

The participant describes how sometimes she has to use his motivation for something else, to support him to transition or complete another task. For example,

“If you want him to do something that you know he doesn’t want to do, as in go home or get in the van. Ehm, I have a Bluetooth speaker. And it’s attached to me iPod. So, one day... I knew he was not going to get into the van. It was looking dodgy now. So, every time he moved away from me the sound went off. You know, because it was Bluetooth. So, when he went to go this way, the music stopped. So, I said, ‘if you come over here, hop in the van you’ll hear the music’. You know, so, sometimes you have to use props, yeah you know, trying to figure out”.

She states that she needs to think about “how not to say something”, explaining that,

“Sometimes, not talking about the thing you want to do is how it happens. So, he kept saying, ‘you come for lunch with me’. You know, and I said ‘yeah yeah’. So, we got dressed up to go for lunch and he says ‘No I’m not going’. So, then we had to pretend we weren’t going for lunch. Then we did go for lunch. So, yeah. Sometimes the thing he says he wants and then he gets it and then he doesn’t want it”.

The participant describes how she uses questions to prompt him to do something. She also pretends not to know where something is, which is enough to prompt him to do something,

“Questions, with X, ‘where is your toothpaste?’... Rather than saying ‘brush your teeth’... ‘I can’t find the toothpaste anywhere?’ You know, you do that ‘he knows better than me’ kinda thing. Ehm, ‘awh, I don’t know where the kettle is’. And then that might prompt him to go fill the kettle”.

When they are travelling in the car, rather than telling him to put his seatbelt on, she will pretend to see a guard. *“So, it’s a lot by association and mimicking and maybe mentioning authority, you might be, ‘oh is that a guard?’ You know and then he might put on the belt”.*

4.5.2 Tuning In

4.5.2.1 Anticipation and Observation

Two participants describe anticipating what the person is going to do, in order to support them. As described in the previous section, one garden participant anticipates how the person might interpret a situation, and that they could be resistant to a situation or demand. *“There is a lot of anticipation... On the days I’m not in, you’re thinking ahead. You’re thinking yeah, ‘how’s that going to go’”.* She describes thinking in advance of her interactions and using different techniques to support him to move through his day.

“X isn’t allowed into the day centre. Ehm, so all the time when I’m working with him I’m all the time bringing him back down to the sheds, focusing him more so on the garden than the day centre”.

Participants report using observation to inform interactions with them in order to facilitate their engagement, *“You kinda look, look and observe right and see the way all of the staff treat them and the staff goes on and I just pick up on that”.*

Three participants explain how their approach has to be very subtle in order to facilitate the person's engagement, with one residential participant providing an example of why this is important,

"I have gone in, ehm, barging in kind of 'whhaaa' I need you to do that, kind of and it's just been a disaster. It escalates, very quickly yeah. So, I have, I've made that mistake, and I'll probably make that mistake again".

4.5.2.2 Use of Person's Mood, Interests and Curiosity

Five participants discussed how they work with the person's mood, giving examples of things that can upset the person, how they respond to the person's mood and how they anticipate their mood in order to inform their interactions. *"When you get to know them, you get to work with what mood they're in".* One day service participant describes how she tuned in to a person and their likes and interests in order to support them when they were feeling overwhelmed,

"I implemented... A worry monster... He's very colourful and he's quite funny looking... He wouldn't like to kinda say that he's worried, cause then, him saying he's worried, would be really focused in on himself and he'll worry about it more. So, with the monster, he sees that's the monster's worry. So, he writes down, he writes it on a piece of paper and then, the worry monster eats it... So, you'd put that in and then he'd close it up and he'd be very sympathetic towards him, 'Awe it's ok, that's gone now'".

All participants discussed the person's interests. A number of the participants discussed using the person's interests to support the person to engage. One day service participant describes dealing with conflict with the person by explaining that she was reminding him of inappropriate behaviour because of his interest in getting a job, *"Relating that back to his interests".*

One residential participant describes watching for people's interests within their behaviour to *"help them develop what they'd either shown they had been interested in by their behaviour".* One garden participant describes how he looks for the person's curiosity and *"if they're curious yano and if they come over, and just start talking about the weather, and all that, and do this, and it just takes off from there... I work on their curiosity".*

4.5.3 Supporting the Occupation

4.5.3.1 Advocacy and Choice

Three participants mentioned advocating for the person in their interviews, with one participant explaining how they support the person to self-advocate,

“One guy wanted to talk about money management and for his parents to be there. So that was more of a structured meeting, and I think there had to be something on paper there to say what we wanted to say and to give him the opportunity to say what he wanted to say”.

Three participants discussed choice within the person’s life, with one garden participant agreeing that the person ‘really does call the shots’, *“and I suppose, a lot of our service users would”*. This participant describes how she provides the person with choice, but within boundaries,

“It’s like choices within limits, you know so giving him choices but ehm, yeah. I did a parenting course called ehm, eh, what was it, it was very good I did it years ago. And it was all about that conflict resolution kind of stuff and about you know, choices within limits. And, ehm, being respectful, but giving boundaries”.

She explains further that the person buys copies of the same film over and over again and advocates that he should be supported to buy, but there should be some taken away too. *“He has about seven copies of Kill Bill. Because every time he goes... ‘awh I love that movie’, and probably has forgotten. So, I think there needs to be a bit around, letting him buy but taking away”.*

One participant discusses whether the person has the capacity to choose which direction his life should take next, stating, *“Trying to figure out... Will he have the capacity to make that choice. Ehm, I suppose I know him very well”.*

One residential participant describes how a person’s ability for making choices and taking responsibilities is *“built up over their life... and, I guess by helping them push their boundaries as well”*. This participant tells the interviewer how he allows the person to decide to engage in an activity or not and respects this decision, saying, *“I might even go, maybe next time. And leave it open. But not leave it as a well we’ve closed a door there, but that you’re not closing doors as you’re going back and forth”*. He does not close the door on the persons opportunity and assures them that there is a next time.

Another garden participant describes how the person has the choice to sit down and relax or engage in the activity. He also describes how he tried to facilitate choice, by finding out the interests of the person and acting on those interests.

"If they just want to just sit down and chill out... And they comes down on a Monday and they do have music on in the, in the Men's Shed and just during the conversation yano, so 'what kind of music do you like?'. And he named off a few things and I said is there anything else that you like? And he talked for a few minutes and he goes yea I like UB40. Now you have to dig for it right, took me now four or five minutes to dig for it. So next week I had a UB Forty tape there".

This participant tells the interviewer his motivation for his work, stating that he cuts the grass so that the person has the choice to walk on it, or not.

"When I started here my job was to keep the grass cut, right and somebody asked me one day... 'Why do you do it?', I said, 'it's simple, right. If the grass is all overgrown and things like that then the residents haven't got a choice. If the grass is nice and cut and neat then they have a choice to walk on it or not walk on it'".

4.5.3.2 Meaningful occupation

A number of participants described activities that have meaning to the person. One garden participant describes a person who attends the Men's Shed and brings biscuits to share with the other people.

"At the end of it we have tea and biscuits, he brings along biscuits... Right but no he wanted the big packet... It's not greed right, they'll all have three biscuits each".

He describes how two people work with him in the garden one day a week. He describes the excitement from one person when he handed him some money for his days' work,

"Yea and the beauty about it is right that I suggested that he gets paid for his work, gets paid for his time... I'm given an envelope with a small amount of money in it. Right, the smallest paper money that you can get... Delighted. He's getting paid for his job".

A day service participant discusses how a person got involved with Slimming World to work on his goal to be healthy. The participant states that since he started, he is less stressed and is like *"A whole different person. Everything just really eased down"*.

Another day service participant describes how the person *"loved"* working behind a bar

on Job Shadow Day, where he learned people's names and pulled pints. *"He was amazing... Like he can remember everyone's name, like straight away. Like he was eh, you know, pouring the, he did the taps and stuff like that. He loved it!"*

One garden participant describes the value that working in the garden has for the person. She describes how he identifies as a worker.

"There's that identification as worker, high vis, work trousers, work boots, definitely... And it's very important for his self-esteem. Because, X either dresses in work clothes, or suits. So, he doesn't really do casual. So, he would see the prop as being, 'oh I'm a worker', or 'I've got a three-piece suit on'"

4.5.3.3 Just enough support

Three participants described how they use trial and error to figure out what support the person will benefit from, *"trial and error... I think, lot of the changes that have happened with me working with him, have been from working a certain way, and it not working as well"*. Another day service participant echoes this, saying, *"you know if you work with them you can understand or you can, you know try different things and eventually find the right..."*

One residential participant describes how sometimes you need to have the arguments or challenging times with the person to actually figure out what the right support is for them, *"Sometimes you have to kind of have that to happen to you to kind of... For you to kind of learn really like"*.

Two day service participants describe providing support to the person that is not too much or too little,

"So, like eh, yeah to be there for them if they need, me. But try to give them enough freedom to you know, that they can try themselves. And, eh, like to, I just love to think that you know like what we are doing, in the future it's going to benefit them. You know to have a kind of purpose or goal that can help them. Because we are not going to be to be there forever for them".

4.6 Theme 3: Relationships are Core

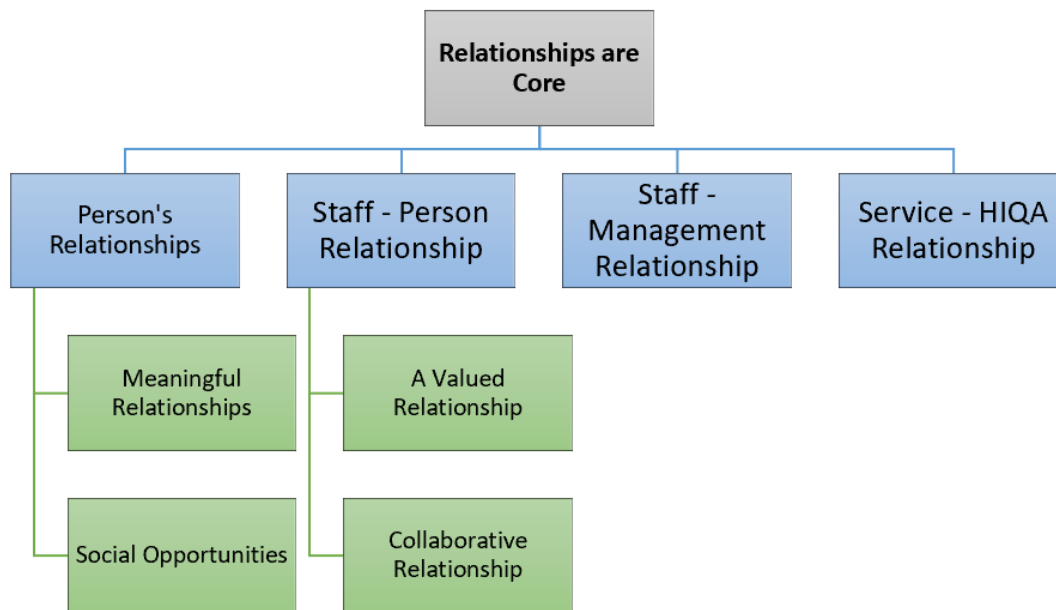


Figure 8: Theme 3 and Sub-themes

The second theme deals with all relationships evident within the data set. The first sub-theme, the 'Person's Relationships', is divided into two parts, discussing the person's meaningful relationships and social opportunities. The second sub-theme presents the participant's descriptions of the relationship between the person and the staff as valued, collaborative and by one as "master-servant". The third sub-theme describes the relationship between staff and management, and the fourth presents the relationship between the service and the Regulator, HIQA.

4.6.1 Person's Relationships

4.6.1.1 Meaningful Relationships

Two participants discussed the person's friendships. One day service participant states that a lack of friends is often a barrier to the people she supports to engaging in activities and occupations.

"Because I think a lot of the service users we work with one of their biggest barriers sometimes to doing things is that they don't have someone to do it with, or they don't have a lot of friends outside the service".

Another states how the person he supports reported that he missed his friends after moving out of the day centre.

“Now what he meant by, ‘I miss my friends’ is a very interesting thing, which experts beyond my capability would well be able to define and exemplify. But what I, because when you do bring the friends, they hardly even talk to each other. So, what does it mean, ‘I miss my friends’? It could be ‘I miss my routine, my old routine, I miss the contacts.’ And he asks about people. But when he meets them, we do not know what is going on there”.

The participant discusses a safeguarding procedure within the residential house, stating that the conflict between residents could be them learning how to make friends, *“It’s what you do with, maybe you’re making friends like that? Like these two guys, we say they’re like teenagers”.*

Frustration regarding ‘de-congregation’ and the impact this has had on friendships is expressed and the example given as, with a recent decision to change the service mini-bus for a car. Now staff cannot take all residents in the car together and other staff have said that *“Ah well we’re stopping all those driving them in buses together. You know it’s not good for them. It’s good for them to go out on their own or individually or in pairs and all”.* The participant questions, *“Is it? Because by golly when they’re in that bus and they’re all together and they did it for twenty years!”.*

Two residential participants touch on how often people do not have any choice in who they live with, *“they didn’t choose each other as housemates, you know. They were kind of put together and hopefully they won’t kill each other, kind of thing. That’s generally how it is in these places”.*

Throughout the interviews, many participants described how people with autism connect with others. Two participants discussed how people can connect through groupwork and shared interests. One participant describes how the person has connected with a group of people through weight loss,

“He’s doing fantastic. And he’s like, since he’s gone to the group, it’s really nice to see because it’s really community based, and before when he first started, people weren’t really too sure what way to approach him. So, they were you know, kind of, oh you know the big smiles that everyone kind of does, ehm, to now, ‘oh hey how are you, awe how did you do this week?’. And like he’s won awards now for

eh Mr. Sleek of 2017. Cause everyone voted for him because they thought he was very inspirational to the class. And not just because of his disability, because of all the weight he lost. Like the disability is not seen, at all. Which is brilliant”.

Another participant describes the unique way people have of connecting with each other. He describes how people like to be together and don't directly interact, but that's not what matters.

*“And they listened, one guy listening to the music and they, and it's not ‘awe we're all together’, it's not. It's autism. They're on their own together. It's a very extraordinary thing. There's a guy that I work with there and he, you look at him, you'll say ‘hey how are you doing’, *disapproving grunting*. Put him in a little group... He likes being in the group”.*

Two other participants described how people connect through gardening tasks,

“See on the day that he's here with us then there's lots of, there's a good few work people around, like maintenance staff... So, he has a lot of banter and he has a lot of chat... it's just getting used to him and him getting used to other people”.

One participant refers to the person's “partner fella” that works alongside him in the garden and describes how people work together on a task, “Now I make up the slabs and the two lads they work well together. One will hand the stones to the other fella to put it in”.

Three participants discussed the person's community. Two discussed the meaning of community to the person. One residential participant reflected on bringing the person to visit his own family where they would share a meal together. But he is not allowed to do this anymore,

“Because we're in this professional era of, and eh I used to bring him to my house, to my sister, for dinner. Not recommended. Not recommended. So, you have that, and that's well you're and it was said, it was said to me by [management], ‘he's not your friend, you're his care worker’. But, it's not, he is a human being, isn't he?”.

This participant also mentions how the person's neighbour has to sign the visitor's book when calling in to say hello,

“The girl who lives across the road who's been calling for years. She now is being asked to sign the visitor's book, and she does it regimentally because she's autistic and she's been told. She's like ‘where's the visitors book I need to sign it’, ‘there you go, thank you’”.

Another participant discusses the development of the Men's Shed, and how at the beginning, management wanted to bring it into the community, but the participant thought that the service had enough of a community to begin with,

"Yea when I started they were trying to put a structure to it (pause) they wanted to. The instruction was to bring the Men's Shed out to, out to the world. Grand yea out into the community and my idea right, ok, yes, in time. But there is a big community here in [this service], with the outreach and things like that, bring them into it. Get that community strong right then you'll be able to push out".

4.6.1.2 Social Opportunities

Five participants discussed using groups to provide social interaction, using groups held inside and outside of the service community. One day service participant states that they support the person in social contact by running groups, *"So definitely group work has been a really big positive thing on our team for social contact"*. She explains the groups are project or goal focused.

"Yea well now they're kind of more project focused, so there's a few people have a shared goal. We had a housing list group there which was kind of boring in a way because the goal was just to get on the housing list. So, they came and we told them about the housing list and getting on the housing list and getting documents together and then when that's done then the group is over. Yea it's good I suppose because we would have had one of those in town where the whole group was to go to the Revenue Office and get a form stamped. But then I suppose encouraging... like that only took about 20 minutes. But then to say OK we're going to leave now but you feel free to go for lunch together or you know. You stay in town. So, I think that does it naturally. Sometimes they might not be as likely to invite each other for lunch but sometimes you have a group that just ends up somewhere and then staff leave. I think that did get a lot of people more comfortable spending time together away from staff. And then they have started to just meet up outside of us as well, which is just great".

This participant describes the benefits of being part of a group, having shared goals and a role within the group, learning skills, but ultimately being socially connected.

"Everyone would sit together at the table, staff and service users, and I suppose it would be quite sociable and relaxed... I mean everyone would sit down at the end... What would usually happen is, during those cooking groups, the service

users would eat what the cooked and staff would just have their lunch at that time. So it would be kind of a social thing then at the end. A lot of the guys would call that group the eating group not the cooking group. They just came for the meal more so than the learning how to cook. But they did learn to cook a bit”.

All participants report supporting the person in their social interactions, however one residential participant did not elaborate past “Sometimes, yea” but later described the people he works with as “Reclusive characters... They don’t... really like engage fully with the way society expects the rest of the population to do, so they’re kind of out there”. One participant described using a social story to help the person understand social norms and boundaries,

“We have, boundaries would be very good, for him. Or, a lot of inappropriate kind of behaviour of wanting to see, maybe tongues and stuff like that. So we’d do him a social story. So, our social story is our kind of, way of going out into the community to reduce that for a lot of our service users”.

A number of participants described helping the person to interact with other group members, supporting co-workers in how to interact with the person and supporting the person to get engaged in the activity. Staff describe scaffolding the person’s social interactions.

“For other people having that activity to focus on and bringing them in and giving them a specific role and asking them to do something and have a bit more of a role as a staff member, makes a big difference. And then over the weeks they might get more and more involved or then they start chatting to the other people in the group”.

“And you know just asking him to come in we’re cutting bits of rope would you mind cutting a couple of bits of rope to this length. And then he comes in and he says ‘oh I think that stunt dummy is cool what are you making?’ and has a couple of sentences back and forth and then he goes back into the room”.

Two residential participants described the conflict that can be present within a group of people, not only within day services but within a residential house.

“Obviously there’s a lot of, negative energy between people as well. In a hub atmosphere, with forty or fifty people. Lots of them have, you know learning disabilities, or ehm, have autism, that kind of thing. So, it wasn’t all plain sailing. But yeah in the home atmosphere you build up those kinds of patterns, hierarchy’s... Who takes what food off what person, that kind of thing”.

Work was also mentioned as an opportunity for people to be socially connected. One participant describes how the person working in the garden *“has a lot of banter and he has a lot of chat... it’s just getting used to him and him getting used to other people”*.

Another day service participant laments at this missed opportunity for the person she supports,

“And he was in a pub... He loved it!.. We tried to get like maybe an hour or two hours per week, for him. Like maybe first just to volunteer, whatever, so not, paid, you know. But, no. so, it’s kind of hard... It’s just yeah, it’s tough”.

4.6.2 Staff-Person Relationship

4.6.2.1 A Valued Relationship

Throughout the interviews, all participants referenced their relationship with the person, with seven speaking about how well they know the person and that this is important. One participant while discussing the great work that had been done with the person, stated that the previous staff had lots of valuable time with him in order to bring about this change, *“Brilliant... He really worked on X. He was with X maybe four days a week. He had even longer with him”*.

Another participant reports that she would try to get to know the person first, in order to know how to work with them, *“my approach would be to get to know the person first, spend time with the person, have like you know, have ideas what could work”*. During one interview, the interviewer asserts, *“But you have your man sussed”*, with the participant responding, *“and he has us sussed too”*, showing that the relationship is reciprocal. One residential participant summarises the pleasure he gets from forming this relationship with the person.

“So, it is a privilege to be kind of be in, you know, to get to know them and kind of be welcomed into their, kind of their homes, you know, build a relationship, fight, get on well, you know”.

One participant reflects on the nature of her relationship with the person, and states that often the person doesn’t necessarily have anything he wants to do with staff but likes to meet for the company. This creates a tension within the relationship as staff feel that their meetings should have a purpose.

"Then you feel like it's just company, which would be fine if it was just once or, every one or two weeks meeting up for a catch up, but if it's every day then that's not really showing him what it's like in the real world and he's kind of relying a lot on staff for that side of things".

In contrast, one residential participant coming from a different context describes a different kind of relationship, stating they would like to take the person places on their day off work, but he is not allowed, *"I have no problem bringing the guy to a show or, we're going to his mammy next week. Not recommended"*.

In some interviews, the participants describe connecting with the person through fun and everyday conversations, such as the participant working in the garden, *"we have great conversations, and said what film he was at on Sunday and tell me the whole story about it"*. The second participant provides anecdotes about the fun she has with the person in the garden.

"He loves, he has a great sense of humour. He opened, we were emptying the lawn mower and he, he, I was taking it and he put the handle, he put the motor back on. And so, all the grass flew all over me. Now, it wasn't dangerous... I let a scream. And he just started laughing and he said, 'you were soaked with the grass'. And I knew what he meant, he meant covered, but and he would go back to that. He likes that daftness, you know".

"Now we, funny, what happened was, one day I brought him home recently. And it was the wrong day... And I had to go back and get him... I was so embarrassed. When we got there, his dad said 'I wasn't expecting him', and I said, 'I'm so sorry, I'll take him back with me'. And he said 'leave him, he's fine he's fine'. But then I rang staff and they said 'no, the staff are on for the whole weekend with him, we can't leave him'. So, I had to go back. So, X got a great laugh out of this. He thought it was really funny. He thought it was hilarious, 'you got it wrong'. So, you know, he loves that notion that you got it wrong".

The participant and the person have shared habits and routines. One residential participant describes going to a café with the person, saying *"You, me, and Bobby McGee, we'll go tonight"*. One garden participant describes how she sets boundaries within their habits and routines, so that his buying or stacking behaviours do not transfer from home to his work place. She affirms, this is because of their relationship.

“He loves buying new things. He keeps buying new DVDs and things. So, that’s something else the staff have to manage with him. But, I, I don’t, I never buy things with him. So, that’s his relationship with me, we don’t buy. And, I don’t bring him into shops to buy. Ehm, or if we’re in a shop he knows we don’t buy. So, that again is relationship”.

This participant describes how the person’s routine can differ between relationships or environments where the boundaries and routines are not consistent, such as his home within the service and their family home.

“And X sometimes doesn’t sleep. Do you know. He might go to bed at four am... You know the way the social norm is we’ll have breakfast. He doesn’t want breakfast. He tends to eat much later in the evening. He’s put on a lot of weight in recent years. And they’re trying to, but it’s like when he eats. He seems to eat late. Then when he’s not sleeping well, I think he’s not, yeah. You know when you’re tired, you tend to eat. So, he eats when he’s tired... Yeah, and when he’s home, his dad seemingly puts him to bed at nine. And he goes. Lights are completely out. The dad has told me this. Lights are out at nine”.

4.6.2.2 Collaborative Relationship

All day service and garden participants described the collaborative relationship between them and the person, regarding making decisions with the person, or allowing them to make decisions regarding activity choices and daily plans. One participant follows the person’s lead in where they will work that day, *“If he decides to mow the lawn well then I can weed in that area. But, if he decides he wants to dig then we go dig in that area”.*

Another asserts that the goal setting process is a collaborative one, where the person has the goal but they add the steps for them,

“It comes from them and from us as well. It’s me who explains the things, you know like ‘ok that’s great you have this big goal, but then we need to do this and this and this so that you can achieve that’. So, it’s kind of a mixture. So, it’s his goal but I’m also adding things to it for him. So that he can achieve that”.

Two residential participants acknowledge how they want to provide the person with the choice of what to do with their day, but sometimes they *“can’t do it”* due to other responsibilities or procedures. One residential participant explains how he always looks

for the person's opinion, *"Yeah, always being open to, the service user's opinion, treating them with the same respect you would want if you were in that position"*.

Three participants state that trust is part of the relationship with one residential participant stating the person will *"come to you as well like... The trust is there... You know, they will come to you and they'll talk about kind of stuff that's bothering them"*. Another participant echoes this trusting emotional support *"He associates me with work, but also a bit of caring. So, he'd talk to me a lot about his mammy. You know, and he'd give me a lot of hugs"*. In addition, this participant is constantly trying to build on this trust, where the person can trust her,

"Being honest with him, I'd love to get to the point where I was being honest with him. And I mean that's trust, him trusting me. So, I'd often say to him 'I'm not bringing you home today, do you think I'm bringing you home? I'm not bringing you home. I promise you, I'm not bringing you home today'. So, on the days I am bringing him home, I never say that".

Five participants described conflict that can arise within the relationship. One participant described how the person can get annoyed with her for always reminding him to be socially appropriate, *"and it really annoys him when you pull him up on it"*. However, she manages this by checking with him again that they had agreed she would do this, *"Do you want me to tell you when you say something that's offensive to me? And he says yes"*.

Another day service participant describes how she prepares herself for the person's bad form when it rains in the mornings. Staff are ready and expecting to experience conflict or upset with the person, but there is a view that they can help them through it. A residential participant concludes, *"I've had a couple of... incidents... in the last two weeks, you know, where I've annoyed them, you know. But that's, that's life, there's, it's a relationship, you know"*. There is an acknowledgement that conflict occurs within relationships and they will get through it together.

However, not all relationships are collaborative. One residential participant, working with people living in their own houses with staff support, reports on it differently,

"Yea well one of the guys actually says, 'Well I don't want to do this with you, I'll wait until [another] staff comes in. I'll do it with [another] staff'. This is all stuff that's sort of happened where boundaries were kind of you know, not adhered to".

This participant further describes conflict that can arise within the relationship as a result of “feeling a bit stressed” where, “Your own common sense goes out the window a bit as well”. He explains,

“You can end up in a kind of, an argument or, going down the rabbit hole a little bit with the lads. You know, they are autistic as well, and it’s that kind of, you know thinking... Some days you’re the best ever, and another day then you’re, you’re an asshole like you know... They’re not going to give, you know, like they’ll dig the heels in”.

Further providing an insight into the master-servant relationship, he discusses the responsibilities held by the person and by the staff. He states that the person doesn’t do household chores such as the laundry or cooking. The participant discusses that even though the person is able to do these chores, they do not believe it is their responsibility, “that’s not my job”. He initially summarises the nature of the relationship as “master-servant”, and later reflects that maybe staff play a more mothering role, “Well I wouldn’t say slave master, more... You’re the mammy. Do you know, there’s a bit of that, for sure”.

However, he describes how his team has come under new management and the perspective is changing, but when he is feeling stressed, it’s often easier not to “battle” with the person but do the chores himself.

“There’ll be a bit more kind of expectations on me, like, to go, ‘OK what am I doing here’, you know. Which is good... Except for the days when I’m really really stressed. Because then it’s just much easier just to do it, you know, or else just get into this kind of battle, because the lads will battle you”.

4.6.3 Staff-Management Relationship

All residential staff referred to the staff-management relationship as problematic. One participant described how their team lacked direction from management, where staff were not supported to work as a team, “part of the problem was a lot of people who were kinda, the last year it’s kind of gone, everyone kind of running with the ball one way, you know”. He described how new staff would come to him for guidance and support, but he felt this should have been the job of the manager,

“They’re coming to you for guidance, whereas, I don’t know if I necessarily am the person to be giving the guidance. Not that I, you know, eh. I would say there’s a bit of a problem with the leadership, in that sense, if you know what I mean?”

This participant describes how *“over a period of time, you get used to things. Certain kind of, it just becomes a bit more, stagnant, day to day”*. However, he is *“cautiously optimistic”* that new management will form a better relationship with the team,

“So, we’re actually in a bit of a transition as well, where management has changed, bringing good ideas, because I think we were getting a bit stagnant for a while. So, I think going into 2018 there’s going to be some good changes coming”.

One garden participant who has a specific set of skills states, *“I think I should have a horticultural job... And that people should come to me to do gardening tasks”*. She states that management are not receptive of her proposal.

“So, that’s not sitting well with management... And I suppose I don’t feel my skills are being used to the best. Do you know. I think I could offer more, within the caring role... And I keep beating that drum and saying to management, I think I would be better if... People saw me as, you know, the specialist I am in my own right. I’m not hoping to work less hours, I’m not do you know, shirking responsibility. But they’re not seeing it”.

This participant describes a distance between staff and management where they’re not listening or seeing the value that this proposal could bring to the service. She describes, *“it wouldn’t be an automatic thing”* for management to provide de-briefing support (described further in Section 4.8).

Another residential participant describes an equally problematic staff-management relationship, but different in that it is authoritarian in style (described further in Section 4.8.3). The participant states that senior management sign the visitor’s book when they enter the residential house. He questions this practice, *“Who are we? What relationship are we developing? For what? Transparency? Absolutely. Maybe the guys coming to fix the drains, visitors’ book. But the [manager] who’s meant to be a support?”*. He offers a solution to this problematic relationship,

“I think management should have a look and not ‘awe have a good look at yourselves you’re useless’. No, just re-appraise. What message are you giving to us about HIQA? About how we’re doing our jobs. About what support is available and what could be available and what we could do”.

This distant relationship is echoed by the third residential participant who expresses relief in having the opportunity to discuss the work that he does with people during the interview, saying *“Thank you very much, that was enjoyable”*.

Interestingly, none of the day service participants mentioned a negative relationship between staff and management. One of these participants described their team working well together, helping each other out with and brainstorming ideas.

“I think we are really good... On the team meetings we would share and help each other, so and there are many ideas that, you know, we try, and so whether it works or not... You know if someone gets stuck... We discuss and we come up with plans or ideas, and then we try them. If they work, that’s great. If not, then again like we try something else... And I think it works here quite well. It’s a small enough team and yeah, we are good at communication”.

4.6.4 Service-HIQA Relationship

HIQA is only relevant to residential services, as described below.

“‘I know you can get them up to date, get them ready and HIQA ready’. HIQA ready? What are ya aiming for management? What are we aiming for? What are we doing? What are, what is HIQA about? Let’s meet HIQA”.

The participant hypothetically questions if there is dialogue between the service and HIQA, stating he does not believe there is. He provides an insight by stating the policies and procedures as a result of HIQA are an *“Enforcement, you’re dealing with enforcement here”*. There seems to be a lack of respect within the relationship, felt within the quote, *“Give it to HIQA and get the bad marks and then move on”*. Another participant reflects this problematic relationship, *“An inspector will... have come out and inspected the supports that they get and all that”*.

This residential participant states that the relationship is not built on trust and collaboration.

“But, I come from the private sector... We had our main accounts, right. And they have their quality teams. And we had, what you call an open-door policy... The quality team would come in once a month, inspect us... But it’s the old story, how you look at this. It’s a work together thing. And that business, that’s high cut throat business. You develop a relationship of trust... The element of trust, of course there’s commercial under your arm stuff as well, but oh, open door policy.

They would come in they'd see how we do things, they could ask me what I do... there was that forensic. And it's very like what HIQA do. But, the relationship was not a relationship of fear".

Here, he juxtaposes the quality control system for a business within the private sector with a service for people with autism, with particular attention to the relationship between the service or business and the regulator. The participant describes how within the private sector, the regulator was a support to the staff working to produce a quality product, which he contrasts to the fear of consequences that HIQA place on disability services.

"That we find, they give us, targets, yeah? And they'd say, 'I want that done in three months'. And we'd do our best. If we don't get there, they're not going to pull the business. They're going to say, 'ok why didn't you get there? Let's work together'. Because some of their experts were better than our experts and they could always tell us how to run our company... And that relationship is a trust relationship. And what I don't get the sense of, and the only people we have that have been sent to us from management, is that HIQA are in that relationship with us... It's 'watch out, HIQA are coming any day now'... this is like 'if we don't get HIQA we get closed down, or you'll be in deep shit'. And there, there could be 'consequences. The fear of consequences? Like eh disciplinary action maybe?"

He acknowledges that *"I can see HIQA is a quality control system but should be there to help us progress and improve the Person-Centred Plan... Well, it doesn't feel like it... You ask anybody working here"*. Another participant agrees with this point of view, acknowledging what HIQA's purpose is, but that in reality it's not really working,

"So, there's certain things, and abuses that HIQA is safeguarding against. Which is great. But, then, it's curtailing that freedom for them to be, well maybe not in all circumstances, but I see in my, in my microcosm, maybe I'm a bit down on HIQA because of my own personal circumstances, maybe it's not an organisation wide thing. But I don't hear too much positivity about them".

4.7 Theme 4: Staff Thinking and Feeling

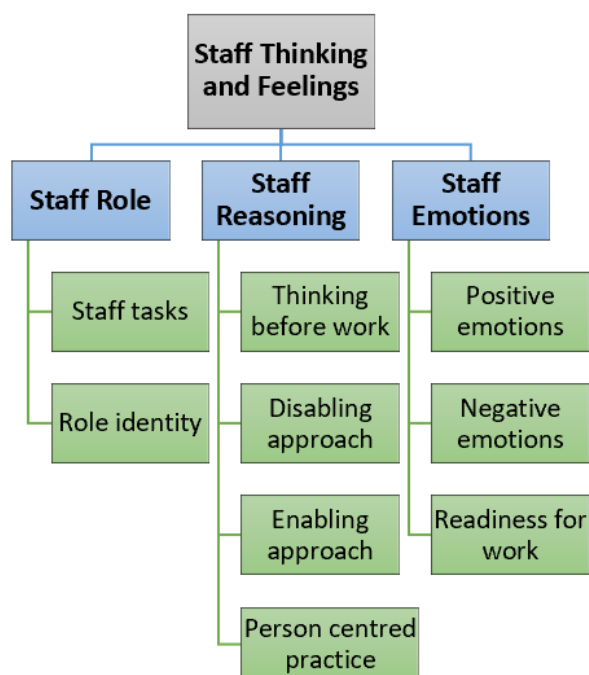


Figure 9: Theme 4 and Sub-themes

The fourth theme in the analysis is titled ‘Staff Thinking and Feelings’ and encompasses three sub-themes. The first sub-theme is ‘Staff Role’ and includes a description of staff tasks and their role identity as a staff member. The second sub-theme is ‘Staff Reasoning’ detailing descriptions about what staff are thinking and how this impacts their work with the person. The third sub-theme is ‘Staff Emotions’ detailing the various emotions felt by staff working with the person.

4.7.1 Staff Role

4.7.1.1 Staff Tasks

All three residential participants describe engaging in household tasks and administration tasks. Two participants working in group homes discuss the tasks that have to be completed daily, such as administration of medication, counting money and paperwork.

“I mean the cleaning and the cooking and the lists of that end of things, between food preparation, food management, cleaning of the house and everything, can take, it eats into everything. Also, money counting. Little things like that and writing in the daily reports. There’s a lot of, lot of, lot of paperwork involved”.

One participant stresses the importance of vigilance when administering medication.

"We do the meds, so obviously that's and that's very strict that that's documented properly. And, if you have to administer any PRN's, so any once off medications. You've got to make sure you're adhering to protocols. So, it's not just writing you have to read to make sure you be doing things right".

The residential participant working with a person one to one, describes how he has to cook for the person.

"We have to cook... They don't cook. One of the guys will, like they're able to use a microwave and all that to you know put something into the microwave and heat it up. But so far as cooking a meal, they don't cook".

Day service participants mentioned tasks in relation to person-centred planning and the persons goals.

"Staff would all read that so they would be up to date. But I guess we would also send out emails if there was something new that came up... Every three months they would have a key working report done up. So that would summarise everything they'd been working on and goals for the next few months".

One day service participant described that they do not have time in the day for many administration tasks, and that their main responsibility in the day is to work directly with the person.

"It's very hard to get what you want, done. You know, especially ehm, person-centred. Like that kind of one to one support, and especially for record keeping. You know it would be, like we would find it very difficult to kind of, you know, implement that through the day. Like, we haven't, as I said, haven't got the support plans and stuff like that. It's kinda been you know, PCP's to be writing up everything like I know other, ehm, around the other areas, they would have PCP's. And then like I do be thinking, oh god like how could, I couldn't even find the time in the day to do that like".

Both garden participants described having tasks to do, such as, *"Tidying up, weeding a particular area, cutting back something, planting seeds, harvesting vegetables, planting up baskets... A lot of the horticultural kind of stuff".* Another participant described having responsibility for taking care of the grounds, *"I was in here on Saturday. I came in to put stuff away for the wind, the wind coming".*

4.7.1.2 Role identity

All participants described their role identity. All day service participants described their role identity as a support to the person with autism. One participant explains that she wants to give the person “tools” for life and provide just enough support for them to participate in daily life, *“I would say that’s the main job, to support them... To support them in a way that’s not too much support”*.

Two residential participants working in group homes describe a similar role identity,

“I want to support them all, I want to support them all. Let them all have a great day. Ehm, get the best out of the day for them... I just want to give them as good a time and understand what their wants and needs are”.

However, they describe difficulties with doing this due to staff tasks. One participant describes how he doesn’t get to support people in activities as much as he would like to in his residential job and states that he wants to move to day service work for this reason.

“I don’t get a chance to do so much anymore. And for that reason, I do want to move into more day service stuff... So, I’m caught in this kind of, I have been very happy there, because we do go out a lot and I was working to help the guys do new things and bring them new places. But it is still their home, and it’s still, you know, they still need to be able to come back and just sit on the couch and be able to do nothing. So I think it works better for me, not necessarily working with the service user, but for me, eh myself, professionally, if I’m in the zone where, ‘this is what we’re doing now’. We are here, to surprise ourselves, we’re here to do some exercise therapy, for the next hour”.

This shows a conflict of role identity, where on one hand they identify with being the persons support to live a meaningful life, and on the other,

“We’re considered food workers. So, our HACCP training means that you know, we’re legally liable if anybody has food poisoning. So, we have to probe the food the same as a chef would... So that’s, you know, we’re food safety workers, we’re professional drivers, we’re, like we’re, medication, like ehm we do the meds”.

This conflict is also seen with a garden participant between what she wants to do during her working day and what she is expected to do, stating she has to compartmentalise her desire to do horticultural tasks and remain focused on the ‘care’ aspect of the job.

“I have to look at the bigger picture of ‘he’s engaging, he’s involved’. Rather than my own agenda of, I want to get this done. That can be conflicting... I suppose I’ve

been here so long and I know that my main role is caring, that I do have to let that side of myself go. The garden part of it has to go".

She is concerned that if the person moves on from working with her in the garden, she might lose her opportunity to do horticulture and "end up" back within day services.

"What I don't want is to end up back in the day centre. As in, just caring. Because really that's not, I don't identify as, that's not what I want to do... So, I could end up back in the day centre. See I am a driver as well. I drive the mini buses. So, I could end up doing the swimming trips".

The third residential participant, working one to one in a person's home, is ambiguous about his role identity. When describing their role, the participant discusses how they previously would have helped them find a place to live,

"But you know to be fair, that's been done for most of the lads a while ago now. But really when you do meet up with them it's kind of more functional I would say. It's kind of gone, as I would have said, a little bit of stagnation there".

He helped the person to find accommodation and get set up with bills and states "that independent living skills would be a big thing you know". Later he states that the person does not cook or clean for themselves. Perhaps his role identity is conveyed in the following quote,

"Kind of like tipping away, doing a few bits in the background... But for the normal day to day stuff, it really is, you come in, you have a list of jobs to do, kind of as staff, checks and what have you... It's just very kind of functional".

However, he and another residential participant describe providing emotional support to the person. One participant describes how he supports the person to engage and try new things, and if the person doesn't engage he will provide them with the opportunity to do it again on a different day.

"It's almost like you are an extra part of their brain, not an extra body there. And you're just trying to like help them in a certain direction. Help them make a decision, where if they were just there, they might be overwhelmed by trees, leaves, just you know. Like, sensory kinda wise, that's enough to distract them. But, you you can help them through whatever path it is".

One participant summarises, "My real job is, is the care but within a horticultural setting. So, definitely, I would see myself as using the horticulture every day in order to enhance people's lives. And to get the best out of them". The second garden participant explains

that he runs the Men Shed on a Monday morning, for the benefit of the people, but also for the staff. He reasons that if the staff can get their tasks done while the person is at the Men's Shed, then the staff will have more time to spend with the person when they return.

"The best thing I can do is support the staff... I'd say to staff you go ahead and do your paper work, right. My way of thinking is right, if they can get the paperwork done. Right, now when the lads are finished, the staff have more time for them. Yano. Just and that's how, just support them in that way".

4.7.2 Staff Reasoning

4.7.2.1 Thinking before work

All day service participants describe how they are thinking about the person's daily plan. One states that if the person doesn't have a plan, she is thinking what options they have and what they could work on together.

"Who is in today... what's their plan for the day. Do they have any plans? Because some of them would go to a course, or they would have something going on. So, what's their plan. Or if they don't have a plan, what kind of options can we, you know, offer. Or, what could they do. Or, what could we work on. So, that's in my mind first, and then they come in and it can totally change".

All day service participants describe thinking about how to prepare for work. One participant describes thinking of the person's goals and preparing herself for how to be with him, *"Different with everybody. But I think with him it's thinking like that... I'm trying to think all the time of that, what are his goals, his goal is to work, his goal is to be as independent as possible".*

Interestingly, there were differences in the responses given from each of the residential participants. One participant describes thinking about preparing themselves for work, making sure they have an extra pair of socks and thinking about the commute. He reports that the first time he thinks about the day ahead and the service users is during the hand over when he is coming on shift.

"Until then, there's no point in having any preconceptions because somebody may have had a bad day when you were in the day before. And they may be in flying form the next day. So, there's really an onus not to bring any, you know, yesterday's negative to tomorrow's shift. So, you know, I learned in the first place

where I was ever working in a day service... that you just start each day with a completely clean sheet".

He approaches each day as a "new beginning".

"I think you have to come in and give all the guys the benefit of a clean slate each day. Or, even each, you know, not necessarily each hour because you do take their moods as they carry on. But, in terms of individual, kinda, individual episodes of behaviour, there's no point in reading into the next day what might happen... And, to dwell on it isn't something that helps I find. Yeah you don't want some cycle of shame, where service users are waking up going, 'no, I was angry yesterday'".

Another participant describes how he needs to prepare himself for the relational element of the job and how stress may have an impact on this. He states that preparing for work is *"very much an individual thing. Now, I would like our team, we would lean on each other quite a bit, I suppose for peer to peer support"*.

The third residential participant and one garden participant, described thinking about what tasks need to be completed and how they will fit them into the day, simultaneously hoping that the person has a good day.

"First of all, you're thinking of OK, what day is it today, who's going where, who am I working with... Because of circumstances we have a lot of relief staff, and there's a lot of staff who don't drive, so you end up doing a lot of driving... Then you know, 'when will we fit this in with everything else?'"

"What's on your mind when you're walking in, well it's 'I hope I get a good run with somebody today'... You come in hoping to do the best you can, knowing that you may well hit on a few bumps in the road. But it's coping with the bumps in the road and maintaining a low arousal and keeping the lads calm and collected and as happy as possible within the resources that you have in that day".

The garden participant adds that she starts thinking about work two days in advance. She is thinking about how to prepare the person for his transitions *"as I say my anxiety starts two days before hand. 'Awe, how am I going to do it, what's going to happen?'"*. Another garden participant describes a feeling that comes over him when he walks into work, *"The big question, right, you walk up that road... I find 30 seconds after walking in that gate a certain feeling comes over me yano... the tranquillity of the <place> just takes over for me"*.

In this participants' work, he remembers that this is the persons home and is mindful to empower them in that vein, *"a thing that helps me help them right is remembering that this is their home right and if I'm in their home. Look at it that way. Empower, I try to empower them. They know it's their place"*. He states, *"I let them free to be free"*.

4.7.2.2 Disabling approach

One residential participant describes potentially disabling practices used by staff, such as, doing the persons laundry, housework and cooking. He described that the person is used to having everything done for them and so does not want to work on goals, *"I suppose I don't know if I was being kind of critical, would say they've probably been mammied a bit, and to go working on goals, that just seems like effort like"*.

This culture of 'doing for' has settled in. The participant describes trying to support the person to do their laundry, but the person does not feel that it is their responsibility, it is the responsibility of their staff.

"A couple of times if you're trying to kind of guide things along into doing something, you know, bring down your laundry and put a wash of clothes on, or you know that kind of way, which they're able to do. And they're just like, 'no, I won't do that, that's not my job'".

He describes the relationship as *"master-servant"*, stating that it is almost easier to do the task yourself, rather than ask the person, and so the cycle continues, *"I've been guilty of it as well, you know, because sometimes in your head you're just like, 'I just want to get through this next few hours, I'd nearly do it myself'"*. The participant questions if the service user will want the 'mammying' to stop.

"The more autonomous they become, the less mammying is needed. You know, the mammying will have to stop, you know what I mean, so whether they want to give up the, because they're not happy about having their houses, you know, being inspected by HIQA, or having like you know their kitchen looking like an office with folders and all that there you know. But, also, they definitely like to be driven around and you know, get this for me, get that for me. That kinda thing".

A day service participant describes staff presence as a barrier to the persons engagement, when describing baking with the person. The person put the buns in the oven and went

to the toilet, where he spent a long time and ignored the cooking time of the buns, because the staff was present to look after it.

“And like, then he comes back and I was saying like look, you know, that wouldn’t have worked if I hadn’t have been here. And he says, ‘Well, thank god you were here’... It can be hard to get them to think that way as well, when you are there. So, trying to take a step back when you are there as much as possible”.

She highlights how the person is very comfortable with this presence.

4.7.2.3 Enabling approach

One day service participant states, *“trying to think if you weren’t there”* is an enabling approach for supporting people to learn skills. She describes how they set up the person’s sessions so that he has to plan and organise himself for the meeting.

“So that he can actually learn to do that for himself and I suppose, not feeling like the service is doing him a dis-service by showing up, and for him to expect that when you’re meeting someone they just show up. Eh, no when you’re meeting someone you kind of have to agree a time, and you kind of have to have contact with them and you have to be there on time, or else it doesn’t really work”.

They are preparing the person for the future. The other day service participants echo this, discussing that they are thinking of the persons future. All day service participants describe thinking of the persons goals to inform their approach with the person. One describes *“giving more responsibility to him to organise and plan things”* so that he is organically learning to take responsibility through just arranging to meet with staff. She uses reality checking with this person, where if he was late for his job, or rude to a person in work, it wouldn’t be ok, *“to bring it back to well, in a job this wouldn’t happen”*.

A residential participant discusses treating the person as an adult, but in a different way to the day service participant and touches on responsibility. He states,

“We’re not asking... them to take responsibilities that they can’t take. But to, address them as an adult. If somebody wants to be called ‘a good boy’, you know, remind them that they are a man. It’s like, ‘yep, you’re a good man’. That kinda thing? Cause you end up with people in their fifties or sixties being called ‘awe good girl’”.

One garden participant describes how his work has grown due to support from the occupational therapist and previous management. He describes how the occupational therapist had a *“totally different way of going on than anybody else here”* and that together with the previous manager,

“The two of them just blossomed, and everything else underneath it started blossoming. And that’s how I got here, yano, these, these people... Getting it, right, cause we’re on the same, same wavelength”.

He describes using an enabling approach to influence staff members, stating,

“The thinking behind it was that on a cold dark Monday morning your coming into work right and when you see the daffodils around it will lift your spirits a little bit and when your spirits are lifted a little bit your able to help the service users”.

He plants flowers with people with autism, where they will be seen, to empower and give the person ownership over the space,

“Getting the benefit from it but getting the recognition for it. That’s important. Go past the flowers the carers saying ‘oh your flowers, your flowers are doing well’. That’s the ideal part about it. Right, not saying the flowers look well, saying your flowers look well”.

Among participants, there is a notion that the person has potential. One participant describes,

“He has a booklet about himself and I was reading it this morning. And, his dad says in it, “I really don’t feel we’ve seen the best of X yet”. And he says, “Just wait for it, just wait for it” ... Oh, amazing. “Just wait for it”, he says, “He could shine yet”. You know, so. And that notion of potential, I suppose. Do you know, that there’s still a chance”.

4.7.2.4 Person-Centred Practice

Many participants discussed the importance of being person-centred in their work. One residential participant responds to the interviewer discussing people being so different and how we know what is right for them, stating that *“it takes a lot of time. It takes a lot of time. It takes a lot of input, investment and time and energy. And all of that”*. He continues,

“It’s not a broad brush. Don’t forget you have an individual here. Eh, one guy will react well to it, some guys don’t like to be told anything going ahead. Other guys do... Each of them are completely, they are just individuals”.

Another participant agrees by saying, *"You really have to get to know very subtle things about someone. And, they interact with each staff member differently. So, what works for one person is not going to work for everyone else. Or, maybe anyone else"*.

All participants give examples of how they interact with the person in a person-centred way, whether they are supporting them to engage in a visual schedule, achieving their health and well-being goals, make choices in the Men Shed, having opportunities or in communication. One garden participant describes how she prepared the environment with music to prepare the person for work and listened when he decided they didn't need music anymore, *"He did say to me after about four months, 'boring!'. And I thought, OK. Now we don't have any music. You know. Now it's ok, there's no music there"*.

Six participants describe experiencing challenges with person-centred practice. One day service participant describes challenges relating to the influence and expectations of the parents of the person, describing a tension in respecting the person as an adult and communicating with parents regarding the person's activity choices and capabilities.

"It's dilemma, that you know they are adults we are working with adults. So, how much more information are you giving to a parent who is actually there, and... So, here I find that one is a challenge, sometimes... Or, the parents has an idea, strong idea, or opinion that needs to be done and what we need to do".

Another day service participant and two residential participants describe staffing and time issues as a barrier to person-centred practice. One participant explains how the difficulty can be rooted in the number of staff, supporting five different people at the same time.

"It's such a balancing act. It's like trying to live life for somebody else. If you're doing it for one person, you have some chance of doing it pretty well. If you're doing it for five people, and there's ten or twelve people doing it, it's complicated".

Another residential participant states that *"Since I've started working here, I've never worked on a person-centred plan. Not one"*. He describes a confusion and perhaps a lack of focus within the service on person-centred planning.

"But with the PCP, I went back to college to do social care, and they were talking about PCP's, and there is PCP's, I've seen them in the press over there... And kind of when I started here, I was told oh we're actually moving away from PCP's, more like support plan, sort of, and now lately I'm hearing OK we're back to PCP's again. But, I've never actually sat down and worked on a PCP. So, I've done, sat down and done goals and what have you, but not a PCP kind of format".

One residential and one garden participant discussed the issue of person-centeredness and organisational decision-making. One participant made specific reference to decisions like the de-congregation of day services and how the person had no choice. The policy was adopted without discussion with the service user about their actual preferences.

The second participant describes a person's routine and how his routine may change, due to an organisational decision that has been made relating to staffing, which has not been discussed with the person, *"I think it's been put forward from, I think from a staff point of view. I feel"*.

Another residential participant discusses the meaning of person-centeredness, questioning should staff do the person's laundry because the person demands? The participant responds, *"They are huge questions"*.

4.7.3 Staff Emotions

4.7.3.1 Positive Emotions

Many participants expressed positive emotions relating to their work. Two residential participants described the pleasure they get from working with the person.

"I'm only speaking my mind but I feel I'm being terribly negative here all the way through this conversation, and I don't feel it in the whole thing out there. In the real world out there... I love this work... I love being the key worker with the guy I'm working with... And I love it".

"But, no I think this is much more rewarding and enjoyable work than what I had done... It's been a pleasure actually do you know. Because you are working with guys that... are kind of reclusive characters you know, living out there... So, it is a privilege to be kind of be in, you know, to get to know them and kind of be welcomed into their kind of their homes, you know, build a relationship, fight, get on well, you know. All that."

One garden participant speaks positively about the person, describing the things he loves and about his *"great sense of humour"*. She states, *"I'm going to miss him. And, I think he's going to miss us"*. A day service participant expresses her delight that the person has found a way to meaningfully connect with his community,

"He's doing fantastic. And he's like, since he's gone to the group, it's really nice to see because its really community based, and before when he first started, people"

weren't really too sure what way to approach him. So, they were you know, kind of, oh you know the big smiles that everyone kind of does, ehm, to now, 'oh hey how are you, awe how did you do this week?'"

One residential participant explains that when supporting people to try new things and have new experiences the person might not engage, *"you might be disappointed, but you might go, fair enough"*. He continues, *"you do want things for people and you do want them to develop, but they want to develop in their own way"*. There is a patient acceptance and respect that people need to develop in their own time.

4.7.3.2 Negative Emotions

Negative emotions relating to the work is reported, by four participants in particular. One residential participant describes sometimes having difficulties within the relationship and describes a feeling of just wanting to get through the shift. Another describes feeling that they're doing a bad job of supporting the person, due to the pressures and expectations of HIQA and management,

"Very poorly. Not what, not if you read the policies and procedures and the expectations of government and HIQA and management here. Ain't possible. Ain't possible... And, I do my best, you know, I really do".

He explains that he has not got the person's support plan completed, due to a lack of time, lack of a well-functioning computer and lack of computer skills. He states that he does not want to do it for HIQA but for the person he is supporting and it frustrates him that it is not done, *"And that really annoys me, because I want, because I'm not thinking about HIQA. I want my support plan and the support plan right for my client, or my service user... That wrecks my head"*. He expresses a concern for the organisation and the direction it is heading in, relating to the style of management and the fear culture surrounding HIQA.

This participant expresses that the culture within the organisation is *"scary"*. He refers to the expectation to read and know hundreds of policies, and the threat of being questioned by HIQA, with a further threat of consequences should one fail the test, *"It scares the hell outa me. I joined the union because of it. When I did the safeguarding course, I said 'man, union time here'"*. He describes the responsibility it is to be a staff member, where if anything goes wrong, he could be questioned.

“Something happens, ‘how did you let that happen, you know him inside out, how could you let that happen?’ That’s what goes through my head. Call me paranoid, but we’re dealing with human beings here”.

He describes negative emotions directly resulting from interactions with management, saying *“I’m a bit upset at the moment because”* management were raising a complaint against the staff. He also describes others within the service, who feel that their work, or the way they work is being questioned by management, resulting in unhappy staff.

One garden participant describes being upset after being involved in an incident, where she describes having been attacked. After the incident, she describes that staff are required to fill out a report which asks questions about what the staff member did prior to the incident, inferring that staff had contributed to the upset. She states feeling *“awful”* after an incident, and that filling out the report does not help, *“It has an impact on you. You know when you fill something out, just after being involved in an altercation”.*

4.7.3.3 Readiness for Work

Three participants state that the work is challenging, one residential participant stating it is *“very”* challenging. One day service participant describes how the people she works with can be intense as they require attention at all times, *“you know, cause our lads would be very, ehm, would really want your attention. Which can be quite hard to do”.* Another residential participant describes how it’s important to be ready for the interaction, otherwise they can have a tough few hours with the person,

“Like, if you kind of go in on shift, one on one... you have to have your boundaries up you know, they will railroad you, like... And if I come in to work say and I’m in good form, myself you know, all is well with me in the world, I can have a good few hours with the lads you know. Whereas if I’m coming in a bit stressed, it can be, it’s like as if they sense it, yeah it can be tough, it can be a tough few hours”.

There is a common feeling among four participants that it is important to talk about the work. One residential participant valuing *“peer support”* amongst his team members as a means to relieve stress, as well as maintaining a good work-life balance. One garden participant states at the end of her interview, *“it’s been great to talk about it”.* Another residential participant exclaims hopefully, *“maybe doing this is the start of it”*, meaning the start of change within the service. He continues to discuss supervision;

"We have supervision here, and when we do, what's the point in having supervision with your team leader? I don't get that. I never understood that. They do say that there's a psychologist that you can go to, but that's. But that's no use".

He infers that if you don't have the chance to air your concerns as a frontline staff member, the outcome will be negative.

"You're afraid to offer any, I'm not afraid to offer, but I feel I'm always being deemed as being negative. But I don't have the answers, like either, and I'm not being negative, but if you don't air these things".

He exclaims, *"this, this is brilliant!"* referring to the reflection he has gained during the interview. He is hopeful that the service is at a point of change, *"Come back to the positive thing, you're here! You're doing this on behalf of [this service], isn't it?... Ah, well this is great?"*.

4.8 Theme 5: The 'Disabled' Organisation

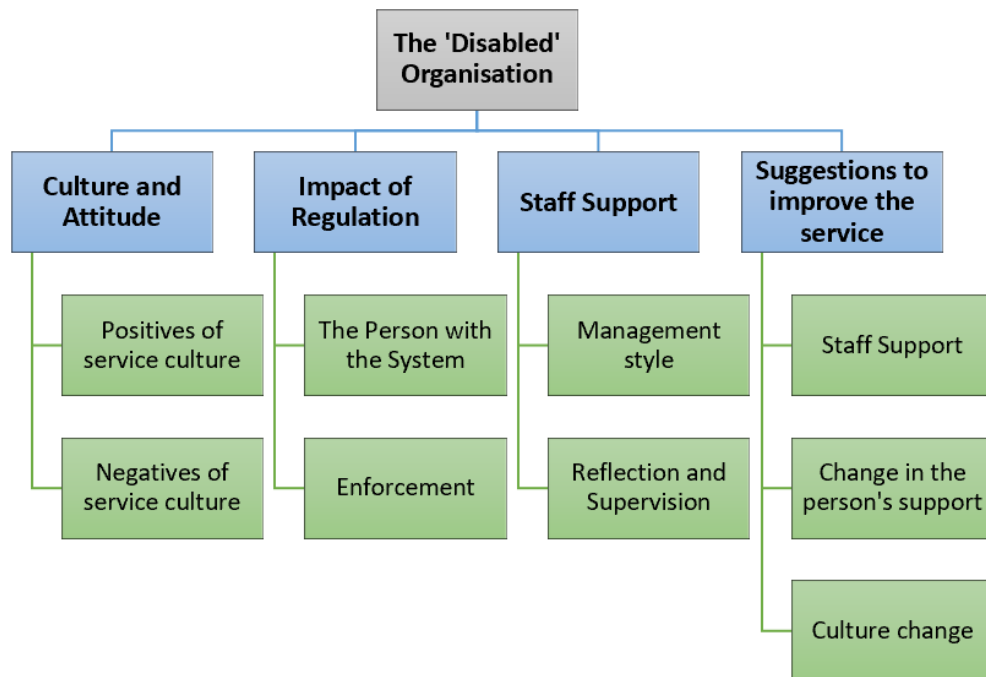


Figure 10: Theme 5 and Sub-themes

The fifth theme is titled 'the disabled organisation' and is made up of four sub-themes.

The first sub-theme details the positives and negatives of service culture. The second details the impact regulation has on the person and the running of the service. The third sub-theme is titled 'staff support', describing the management style perceived by participants. The fourth offers a description of the suggestions offered by all participants.

4.8.1 Culture and Attitudes

4.8.1.1 Positives of Service Culture

A number of participants describe positive aspects of the culture and attitudes of the organisation. One residential participant describes that when he initially approached the service, *"they were looking for people and you wouldn't necessarily need to have experience, and eh it's more about really your personality you know"*, giving an impression of the personality of the service. Another participant asserts, *"I love [this service] ... By golly it's a great place, and their ethos is lovely. I really mean it, I love working here"*. He describes the organisation as honest and shows compassion for the organisation and its weaknesses,

“Because at least it’s being honest. And they are honest. And they’re struggling, struggling. And I think our management might need help... They need, maybe they need help. And that’s, I’m not criticising, but I hope that they, maybe doing this is the start of it. Maybe they need some sort of help, themselves, to manage us”.

He describes feeling *“a true compassion”* from staff within the service within his first few months of work, *“And I did say, genuinely, I felt it here... By the people who were working with the service users. A true true compassion. And also, the management”.*

The residential participant asserts that the service’s values are person-centred, *“there’s no doubt about it”*. A garden participant echoes this, *“I suppose that’s the way I feel the ethos of [the service] is. That we are there to work alongside, and to provide them with the structure that allows them to be the best they can be”*. However, the residential participant worries that this culture *“could be snuffed out because of something that could be turned into something really really positive”*, referring to HIQA.

Another describes how the culture of the service has changed for the better over the past two years.

“Before that there was all of this. It was stuck, it was stuck in the past and... Old ideas right and then when the New Direction was introduced yano certain people don’t like this, don’t like this, yano, maturing yea, and with that came [the occupational therapist]. Right. Totally different way of going on than anybody else here”.

4.8.1.2 Negatives of Service Culture

A number of participants describe negative cultures and attitudes present within the organisation. One residential participant states that Irish disability services are *“streets behind [other country] in terms of how we provide a service, and attitudes, and also just how professional a service is”*. He looks forward to a time in Ireland where,

“The service user who has the ability to split it up and budget the way we have to split up our own money. We don’t give our, all our money to our landlord or bank, and say, ‘I’m at your mercy now, please treat me well’”.

He describes a culture or attitude within the service that infantilises people. However, he is balanced in his view on this subject, stating that some people may prefer this way of being treated by others.

“There can be a tendency to infantilise people a little bit? And, I think it’s, you know, I think it is an easy thing to do... And, maybe some people like that and that’s reassuring for them, but a lot of people who have had breakthroughs in their communication, have come out and said that this has been a negative thing and they feel like they should be treated as a normal human being”.

As previously mentioned, one participant describes frustration with the current culture creating dividing lines between staff and service users, where they’re not allowed to do things together outside the boundaries of their professional relationship. In comparison, another residential participant describes that the person has been ‘mammied’ by staff, resulting in a master-servant relationship. The reported attitude among staff here seems to be one of to care and to serve, and that it needs to change. He describes a lack of leadership and vision from management, and a passivity in staff, which has resulting in a culture that is “stagnant”,

“Well, I suppose one of the guys ... is with the service years... he’s a tricky one to kind of work on stuff like that with, because he really doesn’t want to do, anything. Like I’d say it was the case that a lot of it was done for him”.

One residential participant states, “I hope that protocol thing I’m talking about isn’t the beginning of, a thin end of a wedge”. Here, the participant is referencing enforced procedures present within the residential house where he works and is hoping that this culture is not going to worsen.

4.8.2 Impact of Regulation

4.8.2.1 The Person within the System

Two residential participants discuss the persons chance for a regular life. One describes a situation within one of the houses where two people are “sparing with each other and eh, sussing out the TV rights... It’s been a while, nearly a year. But they are beginning now to [get along]”. The participant is discussing the safeguarding procedures they have in place which he feels are excessive, saying, “I’ve rented apartments with so called friends during my life, and my dinner’s been taken. Hello! Do you call the police?” Later, he discusses safeguarding and reporting of peer to peer abuse to HIQA, exclaiming that it is not abuse, it’s autism,

“This is the peer on peer thing, like by law, according to the safeguarding policy, if a guy, a service user, comes to another service users’ plate and takes chips from

his plate, that's officially peer on peer abuse. And should be reported. No, that's autism".

He is concerned that as each of the 'incidents' are reported to HIQA, the two people are gaining a poor reputation.

"But that's gone out as three occasions as hair was pulled. And now... What worries me, maybe I'm wrong. Maybe I overreact, maybe I shouldn't be in this job sometimes I think because, I have said at team meetings, I've said, this policy and protocol you've put in place here, if we're all gone tomorrow, those two... Those two chaps are marked men in a system. One of them is a hair puller. The other's a chip robber".

The participant asks why we are reporting all of these interactions,

"For HIQA demanding that every incident is reported to them. Every physical abuse is reported to them. And that's a demand. And then it's recorded. So, those guys now are [have a record]. So, now you have 'Big Brother' in action here... I just think God. And that's been going on for nearly 6 months now, and I'm saying, when are you going to end this?"

Another two residential participants question the demands placed on people and services by HIQA. One refers to a person living by themselves, whose house is full of folders and posters impinging on the homely feel, *"Well if that was in my home I wouldn't be having this kind of stuff up, you know, but... it's all HIQA"*. One residential participant discusses changes that were enforced regarding the reconfiguration of day centres, without due regard to each person in the process, their routine and desires,

"Up to, about two years ago they stopped... for 20 years were going from here every morning... that was their life, right. And then that was all stopped with the new-fangled get into your community, no more going to congregated settings, day centres. Wonderful put it up in lights! Deh deh deh. So, I said to X, 'how's it going your new life and everything?'", he replied, *"I miss my friends"*.

He discusses a number of future scandals that we may look back on, first referring to services tendering for people with autism and looking for more resources for their challenging behaviour, *"Do you know what it is, we had the Church forty years ago, this will happen in twenty years' time it'll be on the news, another scandal. All these private companies coming in and they're milking it"*. He discusses the prescription of medication, where the psychiatrist doesn't always see the person.

"I don't think he'd know my client if he met him. He never meets them. How can you do that? These are psychotic drugs! Based on my word and the nurse's word? This is all wrong. This is the next scandal. And it's not [this service's] fault... I love the whole idea of HIQA... Bring them in. But please God go to the government and tell them 'shame on you'. Anyway, that's another day's work".

4.8.2.2 Enforcement

This section depicts the impact of HIQA on the staff's work. There is an acknowledgement among two residential staff that regulation is necessary, but the way it is enforced by HIQA is not suitable to a service for people with autism, *"I do see the value in it. But... I also see it taking away from the guys service, as well"*. Another states that their new priority is to support those living in their own homes to be removed from the regulation of HIQA, stating that this will make them *"more autonomous"*. This participant reports having noticed a change in the model of support the service is working under, and attributes this to the introduction of HIQA.

"When I first came to [this service] there was a lot of a social model of care, you know. Whereas definitely in the last year or so there's more of, stuff that I recognise from my old job, say... Like, key performance indicators and all that kind of thing".

Two residential participants report that the introduction of HIQA has impacted on their time spent with service users, *"It means that as there's more paperwork to do since HIQA came in, that there's less and less time to actually do what the guys want to do, and what might help them feel more fulfilled"*. This participant states that the nature of the work has changed,

"I mean in the two years I've been here it's changed a lot. So, I can't imagine what it was like ten or twenty years ago. The people say, you know, the job has changed, because it's a job now... and, lots of it is to the detriment to the guys service, unfortunately".

Three participants discussed restrictive practice motivated by HIQA regulations, that at times gets in the way of good support,

"So, in the summer time he might have three or four jackets... getting them off can be difficult. So, it can be, again I think there could be more management around

that. There could be more clothes put away. That he doesn't have access to them. But then, that's seen as limiting, as being, a restriction".

Two residential participants discuss safeguarding, one stating *"I did the safeguarding course here, and man, that hasn't even been examined thoroughly, in my opinion".*

Another discusses how practice can contradict safeguarding policies,

"The nature of organisations is that they're risk averse. And, safeguarding policies are that you have to allow people to take risks, because that's a part of life. It's actually written, that people need to be allowed take due risks. But, an organisation doesn't want to take any risks with somebody's safety. So, you find people are actually trying to make somebody safe and they're contradicting a safeguarding policy, by adhering to a certain part of it too much. So, we have policies that contradict each other all over the place".

One residential participant discusses protocols that have been put in place to show HIQA that the organisation is protecting the person. However, he questions when this protocol is going to end, and states that it is having adverse effects on another person living in the house.

When discussing health and safety, there is a difference between residential and day services. One residential participant describes how they are *"legally liable if anybody has food poisoning"*. When a day service participant is asked about health and safety, she appears confused by the question and answers in relation to the person, showing the person-centred nature of how the service is being run.

"I guess we are supposed to fit that in every day? I guess so. Like, you know, like health and safety, like you know they do the cooking. So, you have to be careful how they cook, you know the cleaning".

She explains that they fit the cleaning in at the end of the day when the person is gone home.

The participants working within the regulation of HIQA do not feel it is the right body to be regulating human services, one stating *"they are an enforcement"*. Another agrees with the interviewer that HIQA do not *"quantify"* the nuances and varying person-centred way support staff tune in to people with autism. This participant states that *"maybe HIQA is not the right governing body for a disability service at all and, fingers crossed they'll*

realise that". He provides a number of metaphors to describe what it is like to be a support staff working under the regulation of HIQA,

"It's like self-driving cars... they can do a bit of it. But, but you can still trap them in a circle by bending a circle of white. And then they can't leave because it's a continuous white line".

"It's like introducing a hospital blueprint on top of something that already exists. So, it's like, here's what you built, let's give you our foundations, and put them on top and then we try and like build underneath their foundations, and it's murky".

4.8.3 Staff Support

4.8.3.1 Management Style

One residential participant describes management that is authoritarian, with management telling staff to do things without support or consultation.

"I remember it, when HIQA were coming, 'HIQA are coming!'. All of a sudden, for each service user, we were told we were given a tonne of paper, 'here's the support plan, fill it out'. I started filling it out, huge amount of work involved. Fill it out by hand. All of a sudden, 'oh no, it's coming down online, fill it out online'. 'Oh no no we've changed that, we've done this'".

He describes interactions about paperwork,

"And, then you're just told, 'that support plans out of date, you've got to get it, too much in that support plan. What's that doing there, why have you put that in, that's all wrong'... 'I know you can do it. 45 minutes a shift I know you can do it. You guys did it before you'll do it again'. All that patronising stuff from management. 'You guys, you can do it. HIQA are coming, huhhh'".

The participant provides insight into how staff are perceiving their interactions with management, stating staff feel they can no longer do right from wrong.

"The sad thing is people who have worked here longer than me and all, are beginning to feel, disenfranchised... They just feel very, as if every move they make is being questioned. And they can't do right from wrong. And that's a bad way to have your staff".

Another insight is provided into this management culture and the distance between management and frontline staff, as the participant has heard there is a new manager but he doesn't know his name, *"I don't know his name! Neither do, neither do the parents.*

Neither does my guy, the parents, it hasn't even been announced. Well, I haven't seen any announcement".

Echoing this, two participants discuss how the persons routine can change due to decisions made by management. One participant describes how the persons routine may change, *"But, things are going to change... So, I won't be working with him anymore... He'll have his own staff all the time. So, it's a big change about to happen".* The participant infers that decisions are being made at management level, with little consultation with frontline staff. She also states how management don't see staff as individuals, with individual skill sets that they can offer to the person,

"There's no, and I suppose maybe, does that come from autism, that there's no, they don't see us as individuals in some ways? Management. No. On paper we're just staff. You know, slot in, no chance".

A number of participants speak about management and portray that there is an 'us and them' notion, observed when one participant discusses the requirement to read policies and depicts how they feel they are watched, *"Somebody said to me, 'man you can't go in there, open it and close it and tick it off as read because they know how long you've been at it'".*

This is further permeated with a description of an incident where the participant heard that management was lodging a complaint against a staff member, stating, *"It keeps coming back on us... They're doing things to people that's not fair, it's not fair on [the staff]".* This shows a tension between management and frontline staff, where *"We're trying to look after the guys! And, every time they come down and say 'here's more'".*

4.8.3.2 Reflection and Supervision

Seven participants mentioned challenges and stress associated with the work, for varying reasons. Two day service participants attribute the challenge to communication with families, inclusion in the community and continuity with sessions to achieve goals. Three residential participants and one day service participant who reported staffing issues, also reported that they feel stress. One residential participant discussed how his stress can impact on his relationship with the person on a given day.

A garden participant reflects on being involved in incidents with service users, and how they felt at the time, and how the process after the incident impacted them. She describes how sometimes you may be involved in incidents with a person and can get hurt. The participant states that she feels “*awful*” after the altercation, and that debriefing is not always offered.

“Sometimes there might be a debriefing but sometimes you’d have to ask for that. You know, you’d have to... Yeah, you’d have to build, build. Actually, one time I had, and actually the first person I rang was my husband to say ‘oh god’. I was in the bathroom bawling crying and he actually rang my manager to say, ‘Take X off site for a while’”. You know. So, ehm, I don’t, I don’t know if that’s just with [this service], or whether other care organisations are like that as well?”.

She states, “*You have to mind yourself. You have to definitely mind, you know as a carer you have to mind yourself*”. She takes a long pause to respond to a question about whether management mind staff,

“It wouldn’t be an automatic thing. I think if you, I’m a very, I’m quite emotional and I wear my emotions on my sleeve, so, but I think if you were somebody who didn’t, ‘you’re fine. That’s fine.’ You know you could be taken as, ‘you’re fine’. Yeah, you know, so”.

One residential participant highlights the importance of de-briefing, describing how a de-briefing session from a previous social care job has influenced how he now prepares his mindset coming to work every day “*and I’ve taken that with me ever since*”.

Two residential participants discussed the supervision they receive within the service. Both report that it is not useful, with one suggesting that “*an outside person*” should facilitate their supervision. Another describes it as a tick box exercise.

“We have supervision, I think, 4 times a year... Every three months, but I couldn’t tell ya what we talked about in my last supervision... I find that it’s more of a tick the box, kind of thing. I find more talking amongst my colleagues, teasing stuff out much more beneficial”.

One participant exclaims that the research interview “*is the best supervision I’ve had in years!*”. A number of participants stated that reflection is not something that they do within their teams “*and I suppose when you work it every day, you don’t, you know, [think about it]*”. Participants mentioned that they have a monthly team meeting, but one states that it’s not the right forum for reflection.

"We do talk about it say at our monthly team meeting. But the team has got much bigger in the last year. And it's become, kind of like, you know to sit down and everyone reflect on, you know, peer to peer support, the meeting kind of loses its structure".

There is recognition amongst participants of the need for reflection. One participant states that staff need the opportunity to reflect together and another recognises his need to start reflecting,

"So, I've definitely found that my own ability to self-reflect has dipped the last two years anyway. It's kind of like, now that we're having a lot of change, you know in our team the way it's going to be run for 2018, its, I need to get back into it".

He explains,

"Anything I've ever really learned, while working in social care, it's with, from my peer to peer colleagues. Just, informal chatting. You know. They're the ones that really know. They're the frontline, same as you like... generally we kind of toss it out amongst ourselves".

He describes the process of reflection,

"Some people are just good at thinking a bit more outside the box, or I might be a bit more regimented and that might work in some aspects and it really is, eh what's the word, it's a dance isn't it the whole thing".

Many participants describe the importance of team work. Two describe how they don't receive this sense of team work from the clinical supports within the service.

"We don't really, like any kind of stuff that we've done with the clinical support, it, it, you know, it was 'well that's just autism', like there was a lot of that. So, we would have had a clinical psychologist... but a couple of times I've kind of been in meetings with them about issues the lads would be having, and eh it was generally always just like 'aw that's just autism'... you kind of found yourself in there having to fight it out a bit, not fight it out, I can't think of the word, but kind of, you have to go in there prepared anyway, yeah. Give rationales, plenty of rational to kinda get some support. But generally, I've always found peer to peer stuff was much more successful".

4.8.4 Suggestions to Improve Service

4.8.4.1 Staff Support

Four participants suggest better staff support. Two suggest that staff teams be offered more support for reflection and discussion. One residential participant states, *"We don't get a chance to talk this stuff out"* and suggests that it should occur outside their team meeting.

Four participants state that there is a lot of daily paperwork to do. Another residential participant states that there are more important things for staff to be doing. One suggests the service provides them with administration support.

"Give me somebody therefore to type it for me. Give me some, no no. Here's a shitty old computer that the cursor goes mad on its own and 'Oh well, everybody else seems to be able to do it'. Well I'm having difficulty and the poor [staff] I was referring to there about, [they] can't even switch a fucking computer on".

He states that since HIQA has been, no-one has come to show staff how to fill out the support plan and HIQA are due to visit soon again, *"Got through the HIQA thing, right. Fabulous. It's nearly three years now, HIQA were coming again. No training, nobody's come to visit us. Tell me, the keyworker, how to do the support plan. No".*

A number of participants discussed policies within the service, with one participant focusing on how staff are expected to read them online, having no other way to learn them. He suggests that policies are made more accessible, *"I've asked this before, I said, 'can the company, the organisation, summarise each policy and procedure and put it in a booklet and give it to the front-line staff?'"*.

Two residential participants and two day service participants reported staffing issues as a challenge to supporting the person. The two residential participants reported their teams being short staffed, with one explaining that they use a lot of relief staff, which has an impact on the smooth running of the house, where *"nobody knows who owns what pants"*.

One day service participant working where *"there's only three staff for six lads"*, states that they do not have a break throughout the day, *"You know cause you're not getting that, five minutes to you know kind of relax and just get your... So, like you're coming home then and being absolutely exhausted then"*.

4.8.4.2 Change in Person's Support

One day service participant explains how changes within the community would benefit them, if the community was more autism informed and open to offering opportunities to people. She discusses how staff should work with the person in their home, in order for them to transfer skills learned to their home life,

"Meet at his house and work from there. Because it's lovely that he can cook here. But he has no idea how to do it at home. So, I think I find that it's something that needs to be changed".

She discusses difficulties with communication with the persons family, regarding a difference in expectations. She suggests increased communication and discussion with families, while remaining person-centred and allowing the person advocate for themselves, *"So, if that could be changed and there was a bit more co-operation, or I don't know. And then the flow of information from both sides"*. She mentions that the service could offer family support, to *"make them, less anxious I guess"*.

One participant explains how she wants to use *"horticulture every day in order to enhance people's lives. And to get the best out of them"*. She doesn't feel her skills are being used and suggests that she be removed from the day service and allowed to run sessions, opening the opportunity to more people to engage in horticulture.

Another participant suggests that the Men's Shed be provided with a budget, so that it can continue to grow,

"If I'm looking for, if I need to buy something I have to go and put it down to the garden right so. I'm looking for a budget for the Men's Shed and start going through what house uses it... Who's using it? I said that doesn't matter. The whole place benefits".

4.8.4.3 Culture Change

A number of participants called for a change in the culture of the organisation, in the culture of management, and a re-appraisal of the organisational priorities. One participant suggests that the service remain person-centred regarding decisions that are made which have impact on people's lives, *"So, I suppose improvements would be to keep X to the forefront, keep recognising that he does identify as a worker and as a gardener"*.

Another participant calls for a re-appraisal of how management are interpreting and communicating the regulations and inspections from HIQA, as at the moment it's authoritarian and creating a culture of fear.

Another participant observes new graduates starting work in the service, who are not interested in working outside in the garden with the person and suggests a culture of "getting out and doing it".

"A lot of the graduates coming out of there, yea don't like the idea of getting their hands dirty, thinking I didn't go to college to do that, yano... and I think that is... the getting out and doing it".

One participant advocates for a change in the management structures, suggesting management should not be working on the frontline, as their job is administration and to support staff with paperwork, and he argues that you can't do both.

"I do believe one of the big things that would help is that administration end of things... Change the job of the in-charge person... That's what they should be doing. Administering. Looking at our support plans. Saying here now let's get this bit done. Yeah, we'll do this, yeah lets".

He calls for a quality control system that supports the work of the staff and a management system with open lines for communication and support.

"Yes, a quality control system that's managed, and managed, if there's something that needs to be done, we can't do it without the support... I'll do anything, but don't throw it at me. Mushroom management, I've said and I've been told stop saying that, you know. Well it is mushroom management".

Chapter Five – Discussion

5 Discussion

This final chapter discusses the findings of this study and compares and contrasts them to current research literature. Five main themes are discussed: “The skill of the support staff”; “Person-centred services”; “It’s about relationships”; “Quality and what counts”; and “Management and leadership”. The research aimed to explore staff members’ support of adults with autism in occupational engagement in their daily lives, within the Irish disability service setting. The research objectives were as follows:

- How do staff offer support to service users in participation?
- How do staff offer support to service users in their daily routine?
- How do staff offer support to service users in communicating in their everyday life?
- How do staff offer support to service users in social contact within day to day routines, hobbies and interests?

Occupational science was adopted as the philosophical basis for this study, where all people are understood as occupational beings with an innate drive to engage in meaningful occupation, within the context of their environment. The CMOP-E depicts the person as embedded within the environmental context, which guided the researcher to pay attention to the unique cultural, institutional, physical and social aspects of each person’s environment which can afford occupational possibilities (Townsend & Polatajko, 2007). This theoretical underpinning influenced the researcher to think about people with autism and how they are supported, where ‘being, becoming and engagement’ is often more important than occupational performance (Wilcock, 1999).

The use of the qualitative descriptive approach and conduction of interviews proved a suitable design to achieve the aims of the study, as it allowed for the naturalistic exploration of the unique world of the individual staff member supporting adults with autism (Luborsky & Lysack, 2006). The following discussion points were developed from the five main themes of the study when compared and contrasted with the research literature and the theoretical underpinnings of the study.

5.1 The Skill of the Support Staff

An overriding finding from the study data was less about what staff actually do, but how skilled they are in doing it.

Staff members described their skilled work in supporting adults with autism to explore and work on their personal goals. Each member described doing this differently, showing the individuality of the person, but also the individuality of the staff member. Some staff members showed a reflexivity in their actions and in how they are offering support, with one staff describing how they changed the way the service was set up in order to support the person to take responsibility for himself and improve his planning and organisational skills. This staff member also questions if their presence was a barrier to the persons progression. Staff seem to have a vision for the person's future, particularly day service participants where one participant says, *"I just love to think that you know like what we are doing, in the future it's going to benefit them... because we are not going to be there forever for them"*. This participant states that when working on goals, she gives the person support, but not too much support. This is indicative of the staff using the Just Right Challenge (Ayres, 1983).

The participant's use of the just right challenge is seen throughout the interviews, where staff provide an environment for engagement which is the just right challenge between the skill of the individual and the demands placed upon their performance (Rebeiro, 2001), similar to those described by participants in this study, which have a just right combination of the affirming elements of listening, understanding, caring and social or emotional support, within individual or group settings.

The interactions described by the participants in this study can be seen to reflect Hostyn and Maes (2009) description of quality interactions between people with intellectual disabilities and their support staff. The first component of quality interactions is that of sensitive responsiveness, which is seen in one participants description of how he elicits choice from a person, not listening to the word they say but how they say it. The second component, is joint attention seen in one participants description of interacting with a person in the Men Shed while doing a task. The third component is co-regulation, seen in a participant's descriptions of how she supports the person throughout the day, keeping him focused on the task at hand and using distraction and comedy such as falling over, to shift the person's attention from leaving the environment and back to gardening tasks. Lastly, there is an emotional component involved in quality interactions, which is felt

throughout the participants interviews, with statements such as *“I’m very fond of him”* and *“I’m going to miss him. And I think he’s going to miss us”*, showing a reciprocal emotional component.

Forster and Iacono’s (2014) findings that affect attunement is used by disability support workers with people with profound intellectual and multiple disabilities may also be applied here. The researcher hypothesises that the participants of this study are using affect attunement to support adults with autism, particularly those with higher support needs. The way that participants describe the subtle interactions between them and the person, how they notice the person’s tone of voice, facial expressions and body language relates to the process of affect attunement used by staff in Forster and Iacono’s (2014) study. This finding highlights the skill, or perhaps the natural ability of the staff member (Forster & Iacono, 2014) in interacting with the person with autism, not necessarily related to their level of professional education.

This relationship between the person and the staff member is crucial, as it supports the staff to *“gain insight in their motives, their moods, their problems, their disappointments, their sorrows, their expectations and their hopes”* (Reinders, 2010, p. 31). Without this skilled connection, the staff member will not gain the same level or intensity of insight, which reduces their ability in making the right judgement calls in the complex situations that frequently arise in service users lives (Schuengel, Kef, Damen, & Worm, 2009).

Reinders (2010) highlights how staff members observe, watch and interpret the persons’ physical and emotional state, facilitated by real connection with the person. Reinders (2010) emphasises how the staff member needs to be open for this connection to happen, where staff should let go of preconceptions and expectations and be receptive to what is actually there and actually happening. A participant in Reinders study advises staff to *“empty yourself so that you are ready to listen”*. This relates directly to one participant’s approach to his work where he believes there is *“an onus not to bring any [of] yesterday’s negativity to tomorrow’s shift”*. He aims to start every day with the person *“as a new beginning”*, demonstrating an openness and availability to the person where he is ready to connect with them wherever they are on a given day.

5.2 Person-Centred Services

5.2.1 Person-Centred Staff

An important finding from the study is that the participants all spoke about their work and the person they work with, in a person-centred way.

Koenig and Kinnealey's (2010) 'Inside Out' model, has the person at its centre, encouraging professionals to get to know the individual, their interests and goals. Day service participants describe how they *"get to know the person first, spend time with the person"* and *"explore their interests"*. One participant working in a residential setting explained, *"You really have to get to know very subtle things about someone"*. The model instructs professionals to adapt the environment to support the person's engagement. One participant gives an example of this: *"I'd often play 'Take That' [music] in the mornings. So, that sets up a certain... you know just feel to the day"*.

The concept of choice was addressed throughout the interviews, with each participant offering the person choice in different ways. When analysing the participants descriptions of eliciting choice from people with communication difficulties, the researcher recognised how the staff have a tacit knowledge of the person, how they just know; *"you could tell he wasn't into it"*. Some staff report reading the persons' body language, movements, facial expressions and seeming to just know when the person is saying 'no'. This tacit knowledge is deeply rooted in experience and in an individual's values, emotions and beliefs, and is so ingrained that it is taken for granted and is difficult to articulate to others (Reinders, 2010). It involves subjective insights, intuition and hunches (Turner, 2007), and from the results of this study, appears to be fundamental to the work of the staff supporting people with autism.

Wilkins, Pollock, Rochon, and Law (2001) asserts that client centredness must be understood to exist along a continuum, where some people may be comfortable articulating their needs and directing supports, where others may only be able to make simple choices. The support staff's responsibility then is to understand the person's needs and act accordingly. This was noted within the interviews, where one participant supports a person to return home once a month, but never telling him he is going home (Section 4.6.2.2). This shows how the staff member recognised the person's communication difficulties, their difficulty with transitions, and the knowledge that he loves being at home, demonstrating the invaluable knowledge that is built up over time within the

person-centred relationship, where the person is supported to make choice, but from a further point on the continuum.

Participants showed a patience and respect for the person, with one participant stating that if the person doesn't engage in an activity, he will say "*maybe next time*", offering the person the knowledge that they can come back and try again, there are no closed doors. This air of hope, the "*notion of potential*" is supported by Repper and Perkins (2003) who assert that this perspective is necessary to enable the person to use their gifts to build a meaningful and valuable future. It also fits perfectly with a person-centred approach, where the staff is respecting the dignity, autonomy and capacity for change of the person, allowing the person to move towards self-actualisation, while providing a growth-promoting atmosphere (Wood, 2008).

Analysis of the staff's descriptions of the way they work with the person with autism, indicated to the researcher that they are engaging in an approach with similarities to person-centred active support (PCAS) (Beadle-Brown & Hutchinson, 2016). One participant describes "*kind of flowing*" with the person, and another participant explains that when interacting with the person, "*you just have to let it come and go*". This relates to person-centred active support, where support staff use a 'little and often' approach, working at the pace of the individual, keeping tasks and support simple. In using the approach, the support staff also provides just the right amount of support for the person to engage. The support staff aims to maximise choice and control, just as one garden participant says, "*I try to empower them, [so that] they know it's their home*". The final key principle of PCAS is that every moment has potential, which is seen in this study, with one participant describing a moment with a service user where the staff member attempted to remove flowers planted outside his front door and the person "*went, 'no no no leave that alone'*". At this moment, the staff realised the person valued the flowers being there and stated, "*to me, that's important*".

However, an important part of PCAS is removing the focus from paperwork and from recording what is being done. Rather, the focus is on the person's experience of what happened (Beadle-Brown & Hutchinson, 2016). After analysing the results of this study, achieving PCAS could be a challenge within the residential setting, due to the reported focus on paperwork, procedures and staff tasks required which are unrelated to the person's occupational engagement.

The Council on Quality and Leadership (CQL) holds that person-centred care cannot happen only at the level of the person, instead, quality improvement needs to focus on the entire organisation's ability to support actions and individuals that promote the achievement of personal outcomes for all service users (CQL, 2018). Adopting a person-centred care approach within an organisation is a multifactorial process. It includes issues that need to be addressed, such as opportunities for interaction, leadership changes and an emphasis on staff empowerment (Brownie & Nancarrow, 2013). These issues are discussed within the following sections.

5.2.2 The Impact of the Environment on Person-Centred Care

The staff's reported ability to actually *do* person-centred care seems to be affected by their work site location. The day service participants all spoke about the persons individual plan's, individualised supports and the choices available to the person on any given day. The outreach day services and supports in the garden are organised in a person-centred way and are in line with the New Directions (2012) policy, where the staff's main priority is to *"support the guys... in a way that's not too much support... to give them enough freedom... that they can try themselves"*. The whole day is dictated by the person's plans and choices, where the person can change the plan if they so wish. The participant working in the day service that is in transition from a larger day service to smaller hubs, has this perspective also, but reports that it is not possible because of the staffing ratio.

In the garden environment, there seems to be a freedom, with no mention of paperwork, 'health and safety' or staffing problems. Person-centred care was the central approach of the two garden participants, with one participant describing how she completes her own tasks, depending on where the person wants to work, *"if he decides to mow the lawn well then I can weed in that area"*. There is no sense of urgency in the environment, as in the Men's Shed where the men can *"just chill out"* if they want.

Wilkins, Pollock, Rochon and Law (2001) discuss challenges to person-centred care at the level of the system, with similarities to the barriers reported in this study, such as time, resources, and policies and structures that limit a therapist's ability to practice in a client-centred manner. Participants working in residential services report concern and

frustration in that they want to be able to support each individual person's routine, but often they can't as they have to fit it in around the other service users' plans and the routine of the house. They report that the factors of the environment that pose a barrier are HIQA's regulation, staffing ratio's, bureaucracy, inspections, reporting of incidents, and various other policies and procedures that must be followed.

Becoming person-centred requires more than a declaration from management, it must be truly part of the values held by everyone within organizations (Wilkins et al., 2001). In this study, the residential staff participants, discussed organisational decisions being made without the input of frontline staff. Wilkins, et al., (2001) concluded that service providers need to develop practical strategies for the actual implementation of person-centred care, and to announce an organisational commitment to the approach where everyone walks the walk rather than talking the talk. Wilkins et. al (2001) recommends that services adopt a participatory style of management in order to engage everyone in the implementation of New Directions and to support person-centred practice. The philosophy of the service must permeate all levels of the organisation to facilitate culture change.

5.3 It's About Relationships

What staff do with the person with autism, how they do it and indeed why they do it, was consistently framed by relationships. There was a recognition among participants of the persons' need for authentic relationships, coupled with an acknowledgement that people with autism connect with others differently than their counterparts, but it is no less meaningful, *"it's not, 'awe we're all together', it's not. It's autism. They're on their own together. It's a very extraordinary thing"*. Staff members acknowledged the importance of friendships for the people with autism they support, stating that a lack of friends is one of their biggest barriers to engagement. Staff therefore scaffold social situations for the people they support, setting up groups where the people can connect through the activity, an approach which is supported by Temple Grandin (2006), and by Laursen and Yazdgerdi (2012) who highlight the importance of friendships for people with autism, in fostering a sense of belonging and community.

Interestingly, the topic of the person's community was highlighted by staff members, where staff viewed the person's community as the people and relationships that

surrounds them. There seemed to be a tension between what community meant to the staff member and the person, and what is being pushed by the 'Regulator' and through policy. One participant described this tension, "*the new-fangled get into your community*" and juxtaposed this with the process of de-congregation and the person's loss of friends, indeed their loss of community. The researcher questions if this tension is coming from the New Directions (2012) policy document which states that people should have support "*to get to know people in their community, to live and work in ordinary places, to use local services and facilities*" (p.22). It could be asked if services are focusing on the physical space that the service user spends time, rather than the people they are with and the relationships they are having. Perhaps we would be better guided by the definition of community within the Oxford Dictionary, 'the condition of sharing or having certain attitudes and interests in common', a 'similarity or identity', and 'joint ownership or liability' (Oxford University Press, 2018). This definition is less about the building or space occupied, but rather the people. CQL (2018) state that human services often have difficulty in truly defining what is meant by 'community' and even more challenging is ensuring that people are actually part of their community.

This discussion of community and person-centredness is very interesting and as one participant said, "*it's not a broad brush*". Some participants argue that staff should be allowed to be friends, companions and interact with the person as a "*human being*", not to force them into the role of service user and the "*professional*" relationship that seems to be pushed by management with statements like, "*you're not his friend, you're his care worker*". For people who don't have an innate ability to form and maintain friendships, such as people with autism in residential services, it could be seen as fortunate that some staff members want to involve the person with autism in their own personal lives. To take the person to their family's house "*for dinner*" and perhaps experience real inclusion, meaning and connection with other people, in the natural context of someone else's real life. This experience may allow someone to feel part of another person's life, an experience which may be rare for our Irish citizens in 'human' services, as alluded to by Mount (2009). The question is, are we seeing people with autism as humans, with the same human need for connection, friendship and love, as people outside of services (Mount, 2009)? If so, the 'professionalisation' of social care (Finnerty, 2012) requires more discussion. The issues of protection and safeguarding require more discussion, as services could go too far in attempting to safeguard the person with autism, where they are safeguarding them against the staff member who is employed to safeguard. Services

should heed O'Brien's (1987) advice that the ultimate success of a service relies on its ability to help people maintain and develop positive enduring, freely chosen relationships. Perhaps services should have the person-centred discussion, address risk and safeguarding, engage with the regulator, and allow, or better yet, celebrate people going for dinner.

This perspective on the relationship between staff and the person differs to that held by participants from the Outreach Day Services, who work with people who live in their own, or in their family homes. The people they support do not require the same level of support to participate in their daily lives, in comparison to the 24-hour support provided to those in Residential services, and so are supported in a different way in their relationships. This is evidence that *"it is not a broad brush"* and highlights the needs for reflection on what person-centred care is and how to interpret the current policies for each individual person with autism.

The value of people with autism having relationships with non-professionals has been further highlighted by the inclusion of one community employment staff in this study, working in the garden. This participant described himself as *"just a CE worker"*, which may give the impression that he is not as valuable as the social care workers. However, his skilled natural ability to interact with the people in the Men's Shed and in the garden, as fellow human beings, saying, *"to me, they're not service users"*, he just treats them *"like one of the lads"*. This perspective fits with a person-centred approach, where the person is seen as a person first (Kitwood, 1997). Perhaps within the emerging *"professional era"* cited by one participant and discussed within the literature (Finnerty, 2012), the presence of the CE staff offers an opportunity for service users to interact with ordinary people, doing ordinary things and adding to their experience of community.

Koenig and Kinnealey (2010) recommend occupational therapists to use a person-centred, relationship-based approach when supporting adults with autism. Petry, Maes and Vlaskamp (2005) note that the quality of interaction as experienced by the person being supported, has been said to directly affect quality of life of the person with autism. However, this relationship can become problematic. The findings in this study suggest that if the nature and development of the relationship is not reflected upon by staff and management, it can become misguided (Hinshelwood, 2012), as in one participants' view, where a blurring of boundaries and confusion about where person-centred care comes

into the equation (Section 4.6.2.2). This participant working in the Outreach Residential service describes the relationship between himself and the service users as “*master-servant*”, where staff play the role of the ‘mother’, and the person is the ‘cared for’. It is in this context that it may be hypothesised that this occurred due to a lack of reflection, poor leadership and disconnection from the work at hand.

5.3.1 Organisational Relationships

As addressed in the previous discussion point, all Residential staff participants discussed a problematic relationship between staff and management, incorporating a lack of leadership and a perceived authoritarian, target-driven style of management. Along with this, the participants discussed an ‘us and them’ feeling, where there is a distance between staff and management, which is further exacerbated by a lack of staff support and de-briefing. In addition, as presented in the Results Chapter, the perceived relationship between HIQA and the service is one of fear, a “*fear of consequences*”. One Residential participant discusses how HIQA should be seen as a support to the service, where the relationship is collaborative and where two-way conversations can occur about how to achieve a quality service for people with autism. CQL work in this way, helping organisations to identify their unique strengths and talents, along with opportunities for improvement. CQL’s website states, “*Together we discover what is possible, dream about what could be better, design a plan to enhance organisational performance and create a new destiny*” (CQL, 2018).

From the staff’s perspective, there appears to be little collaboration occurring between staff and management, and between the service and the regulator. This culture does not fit with services that are supposed to be person-centred and relationship-based (Wilkins, et al., 2001). This point will be discussed further in Section 5.5.

5.4 Quality and What Counts?

The fourth discussion point of this study is around quality and what is being measured as quality in human services currently in Ireland. It was clear from interviews with participants working in Residential services, that meeting quality assurance standards is perceived as a large portion of their day to day work. Of particular note, was one Residential service participant describing activities he supported people to engage in

when he previously worked in day services, which he followed by saying *“I don’t get a chance to do [those things] so much anymore and for that reason, I do want to move into more day service stuff”*. The participant describes how he likes helping people to surprise themselves in the things they never thought possible, while also accepting that people *“still need to be able to come back and just sit on the couch and be able to do nothing”*. So, the question here is, are residential services losing ‘activity-minded staff’, who get their buzz from people doing things, to the day services. If so, why? What impact does this have on the residential service user and their experience of a quality service? If residential services cannot retain this type of staff member, who helps the person receiving residential support to *“push themselves”*?

One participant described his concern for the people within residential services, coining those who have been involved in ‘behavioural incidents’ as, *“marked men”*. These concerns of the participant, directly oppose HIQA’s (2013) descriptions of ‘individualised supports and care’ which emphasises people exercising their rights and making choices in residential care. This is interesting as the participants were discussing working within residential houses that have already been registered by HIQA, which would infer that HIQA are missing a link in their assessment of quality within services.

Day services are not yet under regulation (Inclusion Ireland, 2016) and are guided by the New Directions policy which is grounded on the principles of person-centredness, community inclusion, active citizenship and high-quality service provision (HSE, 2012). There are no standards to meet or prove, outside what the service requires around person-centred planning, health and safety, and documentation. Findings from this study show that the roles and responsibilities of Day service and Garden staff are to provide individualised support to the person in achieving their goals, having their own routines and life experiences. Everything else, such as health and safety standards, are framed within the background of personal supports. The staffs’ time is spent planning, supporting the person, reflecting on their support and communicating with the team so that goals are progressed. Residential services however, as shown in this study, are laden with bureaucracy which is reported to be getting in the way of staff providing good quality, person-centred supports.

All residential participants described the increase in paperwork that has been introduced since HIQA came into effect, which has meant that *“all the lovely stuff gets put on hold”*.

In addition, social care workers will soon come under the regulation of CORU (2017), who themselves will demand additional paperwork and time commitments in relation to continued professional development of all staff. The results of this study affirm Jones and Carston's (2016) fear that the regulators have overburdened social care staff with bureaucratic procedures and it is getting in the way of good quality 'relationship-based' practice. It was also found in this study that this has also had an impact on residential staff's perception of their responsibilities: *"What's on your mind is... first of all, you're thinking of OK, what day is it today, who's going where, who am I working with... and so, then you know, 'when will we fit this in with everything else?'... I mean the cleaning and the cooking and the lists of that end of things, between food preparation, food management, cleaning of the house and everything, can take, it eats into everything"*.

In 2017, HIQA released a report exploring the regulation of health and social care services where it acknowledged HIQA's current regulations are not best suited to various different models of care provided to people with disabilities, a view that is supported by the findings of this research study. It is interesting that HIQA report taking a human rights perspective to their work and after analysing the results of this study, it would seem that the occupational rights of residential service users are being impacted by HIQA's regulations and demands made on the service. Participants in the study acknowledge that regulation is necessary, stating, *"there's certain things, and abuses that HIQA is safeguarding against, which is great... But... I also see it taking away from the guys service, as well"*. This view is supported by the outreach residential staff who reports his staff team are aiming to support the person who lives in residential services to remove themselves from under HIQA's regulation.

So, when quality is discussed, what does this really mean? CQL define and measure quality from the person's perspective, through the use of the Personal Outcome Measures assessment. The tool aims to ensure that supports are truly person-centred, by assessing five factors which are: my human security (human rights); my community (to be in, part of and with the community); my relationships; my choices; and my goals. The results of this assessment are used to form a person-centred plan and influence an organisations overall strategic plan.

CQL's definition of quality is simple and clearly defined as measured from the person's perspective. CQL is an organisation whose sole aim is the assurance of the delivery of

person-centred services. HIQA's mandate however, extends across the public, private and voluntary sector of services providing health and social care to all people in Ireland. HIQA's remit stretches across acute and community healthcare, children's services, disability services, older people's services, health technology assessment, and clinical guideline support (HIQA, 2013). Within disability services, HIQA inspect across eight themes, one of which deals with individualised supports and care, which includes the five factors addressed by CQL. However, perhaps this mandate is too wide for an organisation such as HIQA to really understand quality as it is experienced by the person in their day to day lives. Consequently, staff in this study are experiencing regulation as a *"hospital blueprint"* that doesn't quite fit within the messy world of disability services. One participant describes, *"It's like, here's what you built, let's give you our foundations, and put them on top and then we try and like build underneath their foundations, and it's murky"*. The participant states, *"Maybe HIQA is not the right governing body for a disability service at all and, fingers crossed they'll realise that and it'll go specifically to disability"*.

So, within the context of this study, it could be asked, what is HIQA measuring? The participants spoke about money counting, cleaning check lists, recording food temperatures, completing and recording bus checks, recording incidents, following procedures. One participant discussed the person's 'Person-Centred Plan' but referred to this as a physical document and his efforts to get pictures printed for it. HIQA's inspection of person-centred planning was not described as a process of exploration of the person's experiences and goal achievement within their community. So, is this really a true measurement of quality?

The findings of this study support the view that a high-quality relationship between professionals and clients is crucial for quality of care (Reinders, 2010). O'Brien and Lyle-O'Brien (1994) state that *"by suggesting that people could be kept safe and well in settings where strangers can drop in to check on quality of life, current approaches to safety fundamentally misdirect attention away from people's most important safeguard, the safeguard that most service settings are most likely to discourage or disrupt"* (p. 28). Reinders (2010) argues that the current quantitative methods of quality assessment in north-western Europe, understand 'quality of care' as being independent from the staff who generates it. As a result, the assessment of quality renders the personal dimension of professional knowledge invisible, thereby excluding it from managerial attention and

support. This shows a possible link between managers focus on registration and meeting standards, and the lack of focus on staff support, observed within the findings of the current study. Reinders (2010) claims that the current methods of assessing quality are changing the nature of practitioners' support in ways that do not so much enhance quality as destroy it, referring explicitly to the personal dimension of practitioners' expertise.

It is argued that the process of 'knowing' within the practitioner-client relationship, discussed previously as tacit knowledge, is a much more powerful tool than that of evidence-based care. The notion of evidence-based care regards data or approaches that can be used in isolation from the process that generates them, that is the personal dimension (Reinders, 2010). Reinders (2010) affirms, *"No toolkit of evidence-based treatments will bring you the personal insight that you need for getting it right"* (p34).

In light of these findings, the researcher suggests that now is the time for the professional activism called for by Smith (2009), where qualified, reflective and competent practitioners do not act as victims of bureaucracy, but rather as leaders of reform in the social care services of today. At a time where HIQA (2017) have released a document detailing their reflections on current regulation and the efficacy of quality assurance systems within other countries, now is opportune time for action of our social care leaders.

5.5 Management and Leadership

This section contains the following topics, "Staff support"; "Personhood of staff"; "Management and Leadership"; and "Bringing about Change".

5.5.1 Staff Support

Lazarus and Folkman (1984) identified the ability to cope with multiple and often competing demands as vital to social care practice, and so, it is imperative that staff are supported properly to carry out their work. From the results of this study, it was evident that there is a lack of staff support within the organisation. The majority of participants reported the challenging work of supporting adults with autism and some reported a lack of support from management.

Brooker (2003) suggests that relationships between support staff and people receiving supports should be considered as psychotherapeutic relationships and advises that support staff be mindful of their own attitudes towards supporting other people. The relationship between staff and the person with autism permeated all interviews within this study, and participants acknowledged the challenging nature of supporting adults with autism to participate in their daily lives. However, Penna, Paylor and Soothill (1995) found that frontline workers identify job satisfaction as primarily related to their interactions with service users and the perceived progress that is achieved with them. Thus, nurturing the relationships between service users and support staff is essential if a culture change such as person-centred care is to be maintained (Brownie & Nancarrow, 2013).

The importance of establishing boundaries within the relationship between staff and the person was highlighted within the interviews. In light of the new professional era of social care work, the traditional notion of professionalism in which Sloan (2003) states the suppression of emotion is encouraged, needs to be challenged (Finnerty, 2012). Interpersonal connectedness within relationships is necessary for social care work, along with skilled emotion management, rather than emotional suppression. The area of boundary management is of particular importance within this discussion, due to the individualised nature of the work and the reality that support staff work deep within the life space of the person for extended periods of time (Finnerty, 2012). Furthermore, support staff need an ability to form boundaries on an individual basis, depending on the particular needs of the individual service user. This individuality of boundary management was evident within the interviews, where the rationale and means of forming boundaries differed from one service user to the next.

For services to recognise the need for support staff to actively engage in the management of boundaries is not sufficient. Services must provide staff support in this area. At a minimum, Finnerty (2012) states that it is essential that support staff are knowledgeable of the theoretical basis of emotion work, how it functions in practice settings, and are trained to develop and apply practical strategies for emotion management in practice. In addition, services should recognise and account for this element of the support role in the development and implementation of organisational policies and procedures, especially those such as risk management and professional boundary management.

The lack of leadership described by participants within the residential setting appeared to have an impact on staff's approach with service users, of particular note here is the acknowledgement that boundaries were broken with service users and so staff were left in a master-servant relationship. Participants described a lack of staff support and active communication between staff and management, where staff are not getting the opportunity to reflect and discuss.

Findings from this study suggest that supporting people with autism to participate in their daily lives can be challenging and emotionally laden work, and so staff should be offered appropriate resources and support in their work. Clements and Zarkowska (2000) discuss the emotional work of supporting people with autism, where staff's insights can be affected by interpretations of a person's challenging behaviour. Therefore, support staff need time, space and support in taking care of themselves. Support staff need space for reflection, in order to become competent practitioners (McKay, 2009), with continuously developing judgement and decision-making skills.

A structured supervision arrangement, including individual and group supervision may be beneficial in supporting staff to discuss their individual challenges relating to their work (Hopper, 2012). Group supervision is valuable as it means one supervisor does not take the full emotional weight of the transference and countertransference that occurs within the supervision process on their own (Hopper, 2012). These supervision sessions must be a systematic process within the organisation and allow for honest discussion and reflection of all aspects of the work so that the health and well-being of support staff can be preserved.

Staff in this study reported administration and bureaucracy as barriers to the delivery of person-centred care. Management and leadership structures need to collaborate with support staff to find solutions to ensure staff tasks are completed, but most importantly staff are free to provide a quality relationship-based service. This requires open discussion with all stakeholders within the organisation to find solutions.

It is not only pay, working environments, staffing levels and workload that influence staff morale, but also the pressure of work, the satisfaction gained from the work, and feeling valued and supported (Finlayson, 2002). As discussed in the literature review, the management of emotion is complex (Lewis, 2005) and is vital as it can impact on the

performance of the support staff as professionals (Hochschild, 1983). An organisation cannot function effectively if the emotions of its frontline staff are not properly managed.

5.5.2 Personhood of Staff

A recent study carried out with care home staff in England by Kadri, Rapaport, Livingston, Cooper, Robertson and Higgs (2018), looked at the 'unacknowledged persons within person-centred care', namely, the care staff. They found that many care staff are not seen as persons in their own right by their organisations, which is upheld by one participant within this study, who stated that current management do not see staff as individuals, where you are expected to just "*slot in*". Kadri et al., (2018) also found a lack of acknowledgement of the moral work of care, which reduces the complex relationships of care work to a series of tasks, impacting on the care worker's self-worth and self-efficacy, which presents barriers to the delivery of person-centred care. It is concluded that organisations need to explicitly recognise support staff's status as persons in their own right, within quality standards, policies and procedures (Kadri, et al., 2018).

Personhood was central to Kitwood's (1997) literature on person-centred care, where he defined it as "*a standing or status that is bestowed on one human being by others in the context of relationship and social being. It implies recognition, respect and trust*" (p.8). This has relevance to the current study looking at staff supporting people with autism, as they are being directed to carry out person-centred care, with little reported regard for their own personhood, which as discussed above, is so important for their sense of self-worth and self-efficacy. A focus on the personhood of staff may result in improved support to people with autism.

Furthermore, the individuality of both staff and people with autism has been seen within the results of this study. Cook et al., (2016) conducted a study in the UK where they suggested auditing staff's interests and skills, not just those of the service user. It was anticipated that by analysing their own patterns of activity and the value that activity brings to their own lives, staff would be more motivated to reduce experiences of occupational deprivation in the service users lives (Cook, et al., 2016). A second benefit of such practice is that staff and the person can have a shared interest in an activity, such as in this study where the garden participant describes how they are "*a real team*" because "*he loves the garden and I love the garden, and I feel it's a good match for the two of us*".

5.5.3 Management & Leadership

As discussed previously, it is the relationship and the quality of that relationship that is crucial to the person experiencing a high-quality service. This section will continue this discussion while looking at the management and leadership structures within an organisation that ultimately supports this quality, or not.

The management styles described within the interviews differed across work site locations. Within the Outreach Day services, the culture within the teams seemed to be supportive and collaborative, with both participants describing team work and reflection with colleagues as part of their day to day work, such as; *“we discuss and we come up with plans or ideas, and then we try them. If they work, that’s great. If not... we try something else... we are good at communication”*. This infers to the researcher that management and leadership styles seen here have elements of those suggested within the literature review, such as transformational, situational and pedagogical approaches (Jones & Carston, 2016; Male & Palaiologou, 2012). In using these approaches, the leader actively engages with the team, creating a vision to work towards, where staff’s needs are met, the team’s identity connects with the organisations identity and a learning culture grows within the team, facilitated by consistent reflective practice.

However, participants from Residential and Garden locations discussed less productive styles of management. One participant describes authoritarian, target driven, *“patronising”* management in how they are asked to get paperwork completed for HIQA requirements. Another describes never getting the chance to discuss the work and reflect on it, while another states that she does not feel management see staff as individuals, with individual personalities and skills to offer. The participants describe a distance between management and staff, where they are not involved in decisions or discussions about service delivery or service development. This upholds McCarthy’s (2006) statement that the growing governance and management structures in social care has created a challenging environment for both staff and management.

Kleunen and Wilner (2000) state that frontline workers are often denied the opportunity to be involved in decision making regarding the person’s care plan. Not only is this practice not person-centred but it is disempowering for staff and it may lead to

disengagement. The importance of staff feeling part of and connected to their organisation has been discussed by Finnerty (2012), who recommends that organisational policies that actively promote employee engagement and plan to avoid staff burnout, would offer significant benefits. The concept of belongingness not only relates to people receives services, but also those delivering them.

The management style described by the residential participants and the focus on administration, resembles that described by Francis (2013) who also described the detrimental effects of this bureaucratic, target-driven system of management within human services in the UK. Francis (2013) calls for a fundamental culture change, which must begin with leadership.

The main difference between the day service and residential working environment is indeed regulation, and the authoritarian management style reported by residential participants does not fit within a person-centred culture. Munro (2010) advocates for reflective, relationship-based practice to be embraced by social care managers, and only then, through effective leadership, can it become a reality. The researcher paraphrase's Munro (2011) in concluding that *'helping autistic people is a human process, when the bureaucratic aspects of work become too dominant, the heart of the work is lost'* (p. 48).

When researching the measurement of person-centred care within organisations, Brownie and Nancarrow (2013) advise that obtaining information on staff turnover and stability of management will provide insight into an organisations' culture and its capacity to adopt and implement sustainable person-centred practice. The findings from this study support this claim, in that difficulties with management styles and a lack of leadership were seen as a barrier to implementing person-centred care. It is discussed within one interview that the results of poor leadership and management were a service that was *"stagnant"* and where the relationship between the staff and the service user had become misguided and described as *"master-servant"*. Brownie and Nancarrow (2013) conclude that person-centred interventions are multifactorial, and need to include leadership and management changes, as well as staffing models with a focus on staff empowerment.

In conclusion, there is a need for more discussion and debate around current policies that are guiding service delivery currently in Irish society, for example New Directions (2012)

and Time to Move on From Congregated Settings (HSE, 2011). Management in services seem to be adopting these policies without their careful application to each individual person with autism. There appears to be a disconnect between policy, management and support staff, in relation to the meaning and application of policy to person. Services should be reviewing evidence of whether the policies have achieved what they originally set out to do. Iriarte et al., (2016) explored the role of support staff in supporting people to move from congregated settings to group homes and personalised arrangements in Ireland. While positive outcomes of the move were discussed, a risk of simply moving institutional practices from one larger location to a smaller group home was present. Staff struggled with supporting the person to achieve real community inclusion and building real relationships with others, and recommended further training for staff in this area. The results of the current study echo this, with one participant describing how a person with autism told him, *"I miss my friends"* having been moved out of his day service due to the changing policy climate. This highlights the need for discussion and debate of policy at all levels, as to how it should be applied to each individual person, as each person's relationships and sense of community is different to the next, and perhaps the best person placed to lead this discussion is the frontline staff.

How each person is funded and the type of service they receive can mean they are subjected to the ripple effect of regulation observed in current social care services. As one participant in the current study stated, *"all the lovely stuff gets put on hold"* to make way for meeting regulation, policies and procedures. Due to an individual being funded for residential care, their whole day is subject to regulation without the parallel support of professional person-centred relationships, where the flow is interrupted as staff have to complete administrative tasks and tick relevant boxes. The scope of support is different to the person receiving support in day service to those in residential. There is flexibility, and real opportunities for choice and autonomy, because of the individualised funding and environment that is rid of regulation. People in residential care are often not afforded this environment that oozes opportunity. It is clear from the results of this study and seen within the literature that regulation is restrictive, and ultimately is impeding the highly skilled work of the person-centred hearts of support staff within services.

It appears that the management and leadership may be being influenced by regulatory bodies, rather than the professional bodies within social care. The regulator HIQA, is

legally responsible for the monitoring, inspection and registration of designated centres for adults with disabilities in Ireland, to ensure the delivery of safe and quality services to all residents (HIQA, 2013). Whereas, professional bodies have a primary role in the leadership of professionals within health and social care. For example, the mission statement of the Association of Occupational Therapists of Ireland (2018) is to “*promote occupational therapy through leadership, standards of practice, ethics, governance, education, research and advocacy on behalf of its members*” (para. 1). Aligning oneself with a professional body, creates the expectation that one follows their code of ethics and professional conduct. As discussed in the literature review, the profession of occupational therapy is inherently person-centred, and AOTI’s Code of Ethics (2013) demands that a member shall provide client centred, occupation-based and needs led services. So, the regulator keeps everyone safe, but the professional body should keep professionals focused on the philosophical underpinnings of the profession.

Social care practice should be led by the professional body, not by the regulator. Social Care Ireland (SCI) is the professional body to provide this leadership to social care staff, and as social care is defined as being based on interpersonal relationships (Lalor & Share, 2013), this should promote relationship-based cultures within services. The operations of both regulation and person-centred support, within the governance structures of services, needs to be separated.

5.6 Bringing about change:

After discussing management styles observed in the reports of the participants of this study, the two-way relationship between management style and the environment, and staff support, it is important for an organisation to look at how to make change. Plesk (2017) asserts that 85% of the problems lie within the system, where just 15% lies within the control of the individual worker. The system is management’s responsibility, and so, management need to fix the system (Edwards Deming, 1982).

Plesk (2017) advises that when striving for change, identifying simple rules allow for the least amount of anxiety within an organisation, keeping it within the zone of ‘complexity’ and away from chaos. These three simple rules to consider in organisational settings are:

1. Direction-pointing
2. Enabling (incentives and resources)

3. Interactions (how we work and prohibitions)

Plesk (2017) affirms that we must think differently about leading change, where complex and orderly outcomes can emerge from a few simple rules, even without central or hierarchical control. Perhaps the development of a culture like this could replace over-planning, over-control and top-down prescription with simple rules, feedback loops and reasonable freedoms (Plesk, 2017). Within an organisation like this, we would see professional autonomy among social care staff that they so desire.

Plesk (2017) outlines five desirable patterns for organisations to adopt in the strive for culture change:

- **Relationships** built on trust that generates (rather than drain) energy and creative ideas. The relationships in question here would be that between the person and the staff member; the staff team and their management structures; and between the service and HIQA
- **Decision-making** that is clear, fast, and in the control of those with the most knowledge of the issue. In light of the research findings, the researcher advocates for the service user and their frontline staff members to be at forefront of decision making, where hierarchical structures are flattened and collaborative decision making can occur.
- **Power** that is shared and exercised in positive, constructive ways toward a common goal. The frontline staff need to feel part of the organisation, with influence and a say in the overall organisational priorities that will effectively influence the day to day life of the service user they so closely support
- **Conflict** that is open, respectful and welcomed as an opportunity to realize new ways of working. This conflict can be worked through within group or individual supervision and reflection sessions.
- **Learning** that is insightful, coming from an active curiosity about how individual staff and the wider team currently think about and do things, and how we might think and do better.

In light of these recommendations for how complex organisations can achieve transformational change, we know that every system is perfectly designed to get the results that it gets (Plesk, 2017), as Albert Einstein once famously said, *“You cannot solve a problem using the thinking that got you there”*. If we want different results, we must

change the system (Plesk, 2017). So, if we want person-centred practice, we need to begin work on creating a person-centred system.

5.7 Critique of Research Process

A qualitative descriptive approach to this research study was regarded as suitable on completion of the research. It is the opinion of the researcher that the same depth of information would not have been collected from research participants had a quantitative approach been used. In addition, the use of an experienced interviewer from outside the service was deemed a successful approach to the study, as described in the following quote from the researcher's reflective diary:

"The decision to use semi-structure interviews to explore this research topic allowed each individual participant the space to respond and provide insight into their unique experience of the service. After finishing the interviews, I was surprised at how different each interview turned out to be. Each participant came with a unique perspective that the interviewer skilfully explored with them, in relation to the research topic. There is no doubt that using an interviewer from outside the service was beneficial, as she was able to ask obvious questions that I would never have thought to ask, often times offering the most insightful information into the day to day work of the staff member. The lack of insight of the interviewer, into the day to day running of the service, offered an opportunity for the participant to describe their unique service and at times engage in reflection with the interviewer about certain aspects of the service, like one participant coming to the realisation that the relationship between him and the person had developed into master-servant. This depth of discussion and reflection would never have been obtained had I used quantitative methods with a larger number of participants" (Reflective Diary, April 2018).

The decision to interview staff from three different work site locations within the service was deemed useful following completion of the study. There was clarity gained from grouping staff in this way, even though each individual participant's work site location differed within the groupings. It was possible to compare and contrast findings across the work site locations, discussing environmental influences on concepts such as leadership styles and person-centred practice.

Overall, the research process was deemed appropriate and met the aim of this study. However, the study had some limitations which will be discussed in the following section.

5.8 Limitations of the study

Although the study met the aims and objectives of exploring staff member's support of adults with autism in occupational engagement in their daily lives, there are a number of limitations associated with the research.

The study only aimed to focus on frontline staff perspectives and did not include all staff within the organisation, for example, management staff. In addition, the study did not include the voice of the person with autism, which opposes Whalley Hammell's (2013) view that service evaluations and research should seek the client's viewpoints.

This study was completed only in one service specifically for people with autism and so the results cannot be generalised to the wider population.

The study included participants who self-identified to participate, whom may hold particularly positive or negative views on the topic, or who may have a particular agenda influencing their motivation to participate. Those who self-identify may also be different or more articulate than others who did not choose to participate.

A final limitation was that the study was conducted at a time of service change and unease and this may have affected staff's viewpoints. Therefore, the results of this study are influenced by the participants' expectations, past experiences, emotions and motivations (Sumsion & Smyth, 2000).

5.9 Future Research

The service-cliff that is a current experience of adults with autism in our Irish society has been discussed in the literature, therefore a recommended area for future research would be participatory style research to explore what it is people with autism want from services. In addition, the voice of the person with autism and how they are supported to participate in their daily life, should be collected using qualitative methods. Research in this area should have a particular focus on the person with autism and their need for relationships and community inclusion, to inform how services are and should be

supporting this important part of their lives. The organisational priorities should come from research in this area.

In addition, due to the finding in this study that the concept of community is understood differently by different staff within the service, qualitative research into the meaning of community is recommended. Views should be sought from all stakeholders, for example, the person with autism, frontline staff, community employment staff, management, family and friends, and the regulator, HIQA.

Jones and Carston (2016) have called for an audit of the actual level of paperwork burden on staff in Irish social care services and whether this burden is getting in the way of support staff building effective relationships with the people they support. The findings from this study support this call for research, as participants working in residential locations cited the paperwork burden as getting in the way of good quality support.

5.10 Conclusion and Recommendations

Having explored staff members' perspectives on the support provided to adults with autism in occupational engagement in their daily lives, and comparing and contrasting these opinions to the literature, a number of conclusions and recommendations are provided for practice in disability service settings.

1. The skilled work of the support staff was presented in this study and it is recommended that the service adopt the concepts of human flourishing (Gaffney, 2011) for its staff members in order to identify unique and individual skills that staff members possess. The four elements of human flourishing should be used by social care managers and applied to support staff to create an enthusiastic, appropriately challenged, connected, autonomous and skilled frontline staff. However, in order for an organisation to achieve human flourishing for its staff, it is essential that proper staff support is implemented.
2. Staff teams within services require the opportunity to engage in regular reflection sessions (Lalor & Share, 2013), facilitated by an appropriate person. However, considering the results of this study, it is recommended that group reflection sessions should be held monthly or bi-monthly, facilitated by a person who

understands critical reflection and who uses the recommended combined leadership approaches.

3. In addition, there is a need for support staff to be guided in reflecting on their relationship with the person. As discussed in the results and discussion chapters, people with autism have a need for authentic relationships, where support staff have a role. Relationships need to be a focus within services as well as the development and management of these relationships. Perhaps there is value in receiving supports from therapists who understand relationships, for example, those within psychotherapy.
4. The cyclical nature of organisational priorities observed within services needs to be examined as it is disruptive. The service needs to find a way for the relational piece and belongingness to one's community, as defined by the person, to be involved in the organisational priorities. As Finnerty (2012) asserts, as long as organisations continue to depend of frontline staff to deliver services, the relationship between the staff and the person should be a primary consideration and central component of decision making in terms of service delivery, funding, structuring and evaluation. Within human services, the development and maintenance of the relationship could be supported by services actively teaching about relationships and their management, that is, being purposeful in what they are aiming to achieve (Finnerty, 2012). Deep relationships with service users can raise the expectations of the service user, and so these expectations need to be managed in the interest of both parties. Therefore, it is recommended that organisations dedicated to person-centred practice actively engage with the issue of relationships and implement policies and procedures that are necessary for creating strong relationships (Finnerty, 2012).
5. Reinders (2010) discusses on the current methods of assessing quality, which relies on 'indicators' of quality that are measured objectively, meaning that quality of care is understood as being independent from the staff who creates it. Therefore, these methods render the personal dimension of care invisible, thereby excluding it from managerial attention and support (Reinders, 2010). This culture and attitude need to be challenged, and it is leadership that can bring about this change. A number of leadership approaches are recommended, such

as combining transformational, situational and pedagogical approaches (Jones and Carston, 2016; Male and Palaiologou, 2012), which would place the staff, their needs, motivations and vision for service delivery at the forefront.

6. Clinical supports, such as occupational therapists should work in a collaborative nature as part of the staff team. Haines and Brown (2017) suggest that occupational therapists could provide leadership to staff in supporting people's occupational engagement, while simultaneously acknowledging the impact of the elements of the organisational context. This could ensure the natural adoption of an occupational perspective throughout the service culture, thereby supporting the occupational engagement of people with autism.
7. Following the results of this study, it is clear that staff view bureaucracy of residential services getting in the way of good quality person-centred support. It is recommended that management engage with frontline staff to come up with practical solutions to support this reported barrier within service delivery. It is recommended that the service provide administration support to both frontline and management staff, to ease pressure and the focus on paperwork, so that staff are free to support the person's occupational engagement.
8. It is recommended that services engage in an examination of current policy guiding disability services in Ireland today, for example the New Directions Policy (2012), HIQA's (2013) standards and the Time to Move on from Congregated Settings (HSE, 2011) policy. An examination is needed on the interpretation of the policy when working with people with autism who have a need for real relationships, belongingness and community inclusion. It seems to be assumed that current policies are good as they are, without proper reflection about how they should be interpreted for each individual person with autism.
9. In addition, it is the researcher's opinion that the service should begin to explore capacity-building within the wider community. It is well acknowledged within the literature and by the participants in the current study that the community is not an inclusive space for people with disabilities. The service should work on the community becoming a receptive environment for people with autism.

10. This is an uncertain time for people involved in human services today, where there are pressures of performance from different areas, such as management, internal quality assurance, external quality assurance, national policies directing services towards person-centred care and community inclusion. However, the researcher concludes that services should reflect on the real job at hand and project organisational priorities towards the occupational engagement of people receiving services and also for the people at the frontline providing services.

11. Lalor and Share (2013) conclude that with emerging debates about professionalisation and differing notions of what care is, how much we value it and who should be doing it, we need to bring the study of philosophy into the education and practice of social care. It can be argued that this confusion around social care is coming from the fact that social care has yet to develop a coherent and well-recognised philosophical basis (Lalor & Share, 2013), and perhaps this can provide part of the explanation as to the influence of the regulator within social care services. The researcher recommends that services review their own philosophical basis, and ensure that it permeates all operations and structures within the service, with appropriate governance structures to ensure it is felt at all levels and interactions within the service.

12. In conclusion, it is recommended that the organisation adopts an affirmative model of disability. This is one that is a non-tragic view of disability, encompassing positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experience of being disabled (Swain & French, 2000). The affirmative model builds on the social model, through which people with disabilities, indeed people with autism, envisage full participative citizenship and equal rights. Using this model, the person's condition, impairment, or disability is affirmed, then people look towards a future society which celebrates difference, and values people irrespective of their disability (Swain & French, 2000). The organisational priorities should be guided by an affirmative model of disability, coupled with an occupational lens, where people with autism are seen as occupational beings, with occupational needs and occupational rights.

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Appendix A: Ethical Approval Letters

Ethical approval letter from Trinity College Dublin



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Aishling O'Reilly
Discipline of Occupational Therapy
Trinity Centre for Health Sciences
St James's Hospital
St James's Street
Dublin 8

Date: 9th November 2017

Ref: 171001

Title of Study: A study on how you support service users with autism in participation in daily life.

Dear Aishling,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in October 2017. We are pleased to inform you that the above project has ethical approval to proceed.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Prof. Brian O'Connell'.

Prof. Brian O'Connell
Chairperson
Faculty Research Ethics Committee

Dáimh na nEolaíochtaí Sláinte
Foirgnasamh na Colmáice
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

Ethical approval letter from Disability Service Setting

Service Logo

Aishling O'Reilly,
Discipline of Occupational Therapy
Trinity centre for Health Sciences
St. James's Hospital
St. James's Street
Dublin 8

Title of Study: A study on how you support service users with autism in participation in daily life

Dear Aishling,

Following on from our meeting held in October 2017, we are pleased to inform you that the above project can proceed on site, pending approval of Trinity College Dublin Ethics Committee.

Yours sincerely,

A handwritten signature in black ink, reading 'Siobhan Bryan', written over a horizontal line.

Siobhan Bryan

Director of Services

Appendix B: Interview Guide

Interview Guide Version 1



TRINITY COLLEGE DUBLIN
COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH

THE
UNIVERSITY
OF DUBLIN

Service Logo

Interview Guide

Interview 1

Background:

1. How many years have you been working with adults with autism?
2. How long have you been working in this service / service setting?
3. On average, how many service users with autism do you support at any one time/during one shift?

Tell me about...

4. How you support a service user in participation in their hobbies and interests?
5. How you support a service user in participation in their daily routine?
6. How you support a service user in communicating his/her needs?
7. How you support a service user in social contact through different activities?
8. How you support a service user during meal times?

Interview 2

The interview transcript of the first interview will be used as a guide to further explore topics in the second interview. The interviewer will ask questions such as:

- Why do you support the person in this way?
- Tell me more about how you support the person during that task/activity
- What are your thoughts when you support the person in that manner?
- How do you prepare for this engagement yourself? - How do you plan your interaction with the person?
- How do you give support during the activity?
- How do you plan for your use of materials and equipment?
- How do you think about the physical, social and sensory environment?
- How do you know what works for the individual service user?
- How do you know the person is happy with this?
- What about if things don't go well, or work out as you had planned?
- Do you feedback to others about the engagement and the supports?
- How does this fit in with your routine; other duties; reporting and record keeping?
- Is there anything that would help?

Interview Guide Version 2



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Service Logo

Interview Guide

Background:

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Tell me about...

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Appendix C: Summary of Themes

Summary of Themes

Theme 1: Description of day to day practice

Day to day practice is described by participants in the framework of routine and what staff and the person do together, their hobbies and interests, and working on goals. Within the day service and garden setting, the routine is centred around the person and their daily plan. In the residential setting, participants describe a tension, in wanting to support the persons routine but not being able to, as their routine has to fit with that of other service users and staff tasks. Most participants describe exploring the persons interests and supporting them in individual ways.

Theme 2: Relationships are core

Participants discussed the importance of friendship for people with autism and facilitating people to connect through activities. The person's lack of choice in who they live with and their experience of community is discussed, referring to visitor books and restrictions on visiting staff homes. Participants discussed supporting the person to connect socially and engage with their community. A strong thread emerged of the importance and value placed on the relationship between the person and the staff member, where collaboration, fun, trust, boundaries and conflict feature. The relationship between staff and management was described as authoritarian, lacking leadership and support. Participants suggested communication as a solution. The relationship between HIQA and the organisation was questioned, with participants asking what are HIQA measuring, calling for communication and support.

Theme 3: Staff support the person to engage

Participants describe communicating with the person, through conversation, writing, texting, using visuals, body language, facial expressions, and listening for emotion. Participants described communication that was so individual to the person, it did not fit within the parameters of verbal and non-verbal.

Participants described tuning in carefully and patiently to the person, supporting them in their day, observing and anticipating to elicit choice and emotion. Participants described preparing and planning for engagement, by preparing materials, preparing their own head

and setting up the environment. There is recognition of meaningful occupation and providing the person with just enough support so that they can engage and learn skills for life. Participants advocate for the person and provide choice in their daily lives, with appreciation of capacity.

Theme 4: Staff thinking and feeling

Participants described the tasks that need to be completed daily, which for residential participants were tasks like administering medication, cleaning, cooking, meal planning, doing vehicle checks, filling out tick sheets and writing in daily reports. Day service participants described tasks associated with the persons goals and do cleaning tasks when the person goes home. In the garden, tasks can be completed alongside where the person chooses to work. Participants role identity conflicted with their descriptions of their tasks. All participants described a similar role identity of supporting the person, but two residential participants described difficulty due to staff tasks and responsibilities.

Most participants described an enabling approach, thinking about the persons future, their goals, responsibilities, treating them as an adult and believing they have potential. One participant described a disabling approach within a 'master-servant' relationship, where staff do tasks for the person, such as cooking, laundry and driving. The concept of person-centeredness was discussed and how this is affected by the organisation.

Participants described negative and positive emotions. Most participants described joy in the person's engagement, interactions and developments, with one participant saying he loves working in the service. One participant expressed feeling they're doing a bad job, feeling scared within the current fear culture, and another participant describes feeling awful after incidents. There was agreement that the work is challenging and staff need an opportunity to talk, discuss, de-brief and reflect.

Theme 5: The disabled organisation

Attitudes and culture were described as positive, that the service has a good personality, it used to be compassionate and has good values. However, negative attitudes and culture were described, in that the service is streets behind other countries and moving towards a professional era where there are dividing lines between staff and service users. One participant described his service as stagnant. Authoritarian management was

described, regarding decision making, interactions and a presence of an 'us and them' notion. There was concern for the person within the residential system, who are considered 'marked men' constrained from living a regular life. The impact of HIQA on residential houses was discussed, with reference to policies, procedures, health and safety, paperwork and safeguarding measures. Participants called for improvements in staff support, collaborative management, reflection, changes in the persons support and the overall organisational culture.