

## **Chapter 1: Introduction**

The purpose of this study is to make visible and recognise the value of disability support work and its place within the social professions. It will examine the experience of staff across the disability sector in Ireland, the contextual influences on their practice, the specific challenges of the work and how these are addressed within employing organisations. The west of Ireland is focussed on as it has a range of long established supports for people with disabilities. The perspective of the worker was of particular interest to me because I am employed as a Disability Support Worker.

Social care became a recognised profession in the Health and Social Care Professionals Act 2005 and the Social Care Work Registration Board has recently been established by CORU leading the profession closer to regulation. Official policy is now focused on empowerment of people with disabilities to live independently and in this context disability support workers operate in small group homes or in the homes of individual disabled people requiring support. Many people with significant impairments continue to require high levels of personal care and support. The Disability Support Worker therefore operates at the intersection of the public and the private sphere where issues of independence and dependence, support and care, professional and personal boundaries are continually negotiated. These tensions are central to the identity of the disability support worker and form a central axis of this study.

### **1.1 Aims and objectives**

1. Explore how disability support workers interpret their role and construct their daily experiences in their working environment.
2. Identify the challenges experienced by disability support workers and evaluate mechanisms of support afforded to them at an organisational level.
3. Examine the contextual influences including legal and policy on the practice of disability support workers.
4. Critically assess the relevant theoretical perspectives and how can they be used to gain a greater understanding of disability support work.

## **1.2 Overview**

Chapters two and three present a comprehensive review of the literature. Chapter two seeks to understand the approaches to the care and support of people with disabilities by exploring historical developments through to the present day. It examines how the medical and social models are operationalized in practice and examines the development of the role of the Disability Support Worker within the current policy context. The debate between care and independence is explored drawing on the perspectives of disability activists. Language and its effects on practice are critiqued to identify the extent to which language influences and is influenced by current ideals in social care.

Chapter three discusses key factors affecting the role of the DSW. Contentious parallels are drawn between mechanical labour processes and the job carried out by DSWs on a daily basis with consideration given to the role of line managers. The gendered nature of DSW is examined as is the physical and emotional labour involved in the role.

Chapter four describes the research approach used in the study. It outlines the research philosophy and provides a rationale for choosing qualitative methods. It describes the various research instruments used, including sampling strategies and qualitative one-to-one semi-structured interviews. This is followed by a discussion on the ethical considerations, validity, reliability, credibility and limitations.

Chapter five presents the findings from the study in two sections. Section 1 outlines the six key themes arising from the findings of interviews with DSWs. Section 2 outlines the four themes arising from interviews with managers.

Chapter six addresses issues that emerged in the findings and discusses their saliency and impact. A particular focus is given to the relational aspect of the work, the professional identity of the worker and how their role is constituted through particular aspects of time. Policy priorities and the influence of current neoliberal ideals and managerialist practices are explored.

Chapter seven reflects on the outcome of the study and presents some conclusions; on how DSWs experience and interpret their role. Recommendations and implications for future research are outlined in this regard.

## **Chapter 2: Towards an understanding of disability support approaches**

### **Introduction**

This chapter provides a historical context of disability support, explores key models of care and examines the influence of language. The first section traces transitions from charity to rights based approaches with particular reference to Irish legal and policy developments. The second section defines and compares the medical and social models and describes how they work in practice. The third section explores contemporary debates around care and independence. The final section explores the evolution of language that is largely indicative of a changing landscape. It critiques the use of particular terminology and examines the implications of language for practice. The status of the worker will largely be determined by the status of the group with whom they work. Thus, by developing an understanding of approaches to disability, we can gain a greater insight into the implications of such changing perspectives for the practice. The term ‘people with disabilities’ or ‘disabled people’ will be used interchangeably throughout this thesis and can be taken to include people with physical, sensory and learning impairments.

### **2.1 Historical overview**

The social construction of disability began with exclusion, medicalization and institutionalization among the underlying principles (McDonnell, 2007). The Priory of St. Mary’s of Bethlehem in London, later known as Bedlam was founded in 1243. It was to be a hospital that solely confined those with psychiatric illnesses but eventually became one of London’s greatest tourist attractions, where wealthy people viewed and annoyed the inmates for entertainment (Davison, et al. 2004: 9). Benjamin Rush (1745-1813), who began practicing medicine in Philadelphia, hypothesized that ‘lunatics’ could be cured through fear. One such procedure was described as follows ‘On his premises stood a tank of water, into which a patient, packed into a coffin like box, pierced with holes, was lowered... He was taken out; rubbed and revived-if he had not already passed beyond reviving’ (Deutsch, 1949: 82). In 1793, Philippe Pinel introduced more humane treatments, replacing chains with straitjackets and dungeon like spaces with light airy rooms. However, this was reserved for the upper classes.

Foucault (1988) believed that while psychiatry was in its infancy, psychiatrists modelled asylums into hospitals so they could gain higher status and professional credibility by aligning their practice base with those of an established medical profession. Mental patients' deviance in society could be used to justify locking them up. In his view, psychiatry assumed responsibility for identifying (or diagnosing) and supervising those who could be considered dangerous from both penal and medical perspectives. Institutionalization creates an experience of powerlessness for people with disabilities (Morris, 1991). Loss of freedom and autonomy, depersonalization, low material standards and social stigma have all contributed to grossly multiply the impact of their impairments.

During the feudal period in Britain people with disabilities were not necessarily precluded from work but with the industrial revolution they were unable to keep up with the fast pace required in production and began to be gradually excluded from participation (Barnes, 2012). People with disabilities came to be viewed as different or 'abnormal' compared with the 'normal' population and as a result were segregated into large institutions where the mentally ill, old and poor received 'care' (Haralambos and Holborn, 2008). Coercive confinement emerged as a response to social deviance and people with disabilities were often institutionalized against their will (O'Sullivan and O'Donnell, 2012). In the 19th century, there was an increased demand for specialized institutional care for people with disabilities and/or mental health difficulties. This demand came from families who could not cope, workhouses, reformatories and prisons where recidivism was seen as a sign of mental ill health. Concerns arose in the early 20th century that 'mental defects' or 'feeble mindedness' was hereditary and could spread if it was not contained and this was used as a justification for institutional segregation (McDonnell, 2007).

In pre-industrial Ireland, people primarily lived in rural areas and relied on agriculture for a living. Unlike Britain, industrialization did not come to Ireland until the latter half of the 20th century. Care for older or disabled people was typically provided for within the family unit (Bilton et al. 1996). Irish population growth accelerated in the 1800s and a consequence of this was that space to grow crops became increasingly limited. Potatoes were the staple food so the potato famine led to devastation (O'Connor, 1995). The earliest form of government intervention was the workhouse, a feature of the Poor

Law Relief Act 1838. The workhouse was a response to the abject poverty that was commonplace at the time and was reserved for the markedly destitute (Powell, 1965). When a 'pauper' was admitted, they were assessed. People with social, emotional or psychiatric difficulties were immediately placed in the infirmary with the 'lunatics' or idiots'. When the workhouse declined at the turn of the 20th century, they instead took on the character of 'hospitals' and county homes'. The religious orders emerged as the key providers of 'care' for this group (Lorentzon and Bryant, 1997). Religious affiliation was seen as an important qualification as clergy were assumed to possess virtues associated with Christianity (Petrie, 2006). The Brothers of Charity were established in Ireland in 1883 as providers of mental health services and in 1938 developed services for people with intellectual disabilities. The Little Sisters of the Poor and the Little Sisters of the Assumption were established in the 1890s and were the first community based care organizations in Ireland (Timonen and Doyle, 2007). However, institutional provision remained the dominant response to need until the 1970s in Ireland (Kennedy Report, 1970). Many people with disabilities lived much of their lives in institutions such as psychiatric hospitals.

O'Sullivan and O'Donnell (2012) suggest that institutionalization prevailed for so long in Ireland for 3 reasons: (i) a failure on the part of the State in their duty of care by committing people to institutions without follow up supervision; (ii) the dominant influence of the Catholic Church as the main provider of institutional provision and (iii) families who were ashamed of the stigma and unable to afford to support the family member with such complex needs.

In the late 1960s, people with disabilities in the UK were inspired by the civil rights movement. Paul Hunt (1937-1989), a resident at a care home led fellow residents in a campaign for control over their own lives. He founded the Union of Physically Impaired against Segregation (UPIAS), the first organisation of people with disabilities (Disowned and Disabled, 2013). Movements such as this gained momentum over the following decades and continued to put pressure on the British government to improve conditions and end discrimination. In the 1970s in the UK, there began a move towards institutional closure due to increasing incidents of abuse, poor conditions and understaffing and inspired by Laing and the anti-institutionalization movement in psychiatry (Ingham and Atkinson, 2013).

In Ireland, there was a gradual shift in legislation and policy developments to promote greater respect, equality and dignity for people with disabilities. This was largely influenced by social changes on a British and European level in relation to disability. It can be argued that Ireland was slower to change than its UK counterparts. Articles 40-44 of the Irish Constitution (1937) specify that no person shall be unfairly discriminated against, directly or indirectly, on any ground including disability. However, this did not have much power without supporting legal and policy provisions to enforce it. Key influences in activism for the change process include the foundation of the National Association of Mentally Handicapped in Ireland (NAMHI) in 1960. It developed as an advocacy organisation for people with disabilities. In 2006, its name was changed to 'Inclusion Ireland' to exclude the term 'mental handicap', which they considered outdated and to reflect its affiliation with Inclusion Europe and Inclusion International; both are organisations for people with disabilities (Quin and Redmond, 2003).

The National Rehabilitation Board (NRB) was established under the National Rehabilitation Board Establishment Order 1967 with the purpose of supervising and operating living, health and training services for people with disabilities. Membership with the European Union has led Ireland to make changes under their direction. After Ireland joined the previously titled European Economic Community in 1973, community actions, specific to disability and focused on integration were formed. The Green Paper on services for Disabled People was published in 1984. It is worth noting that the more inclusive term 'disabled people' is used rather than 'the disabled' or 'the handicapped', which was common terminology in official reports up to this time. The 1984 report is significant because it looks at the overall needs of people with disabilities, such as housing, transport, education and employment rather than focussing entirely on health. Recommendations for inclusion and accessibility were made and responsibility was placed with the NRB to drive the agenda for implementing recommendations, such as assessing accessibility in public transport. However, in the years that followed, they had limited success. Quin and Redmond (2003) note that a key weakness was the separation between leaders in driving the change and the people responsible for areas of policy and service delivery.

The Forum of People with Disabilities was founded in 1990 after 300 people with disabilities assembled in Dublin to express their anger at the denial of their social,

political and cultural rights. Up until this time people with disabilities were viewed as being in need of services rather than independent citizens capable of making their own choices (Killeen, 2014). The forum was influential in seeking equal rights and brought about a change in legislation to abolish the requirement to have a medical certificate of sanity in order to vote, for example. An ad hoc meeting of European Union ministers in Paris in 1991 reiterated its policy on integration of people with disabilities. The ministers agreed that every global policy must ensure accessibility to ordinary services, buildings and transport; guaranteed income support and freedom to make their own choices and have a voice on issues affecting their lives.

*Needs and abilities: a policy for the intellectually disabled* was published in 1991 at a time when the departments of industry and commerce, education, justice and labour were taking a greater role in addressing the particular concerns of people with disabilities. The idea was to transfer service provision from the health sector to mainstream public providers (Needs and Abilities, 1991). It was argued that 'large numbers of highly dependent, intellectually disabled people should not be placed in one location' (1991: 39) but rather recommended more homely settings with no more than four average sized houses clustered together in community based accommodation (Needs and Abilities, 1991). It was also recommended that staff structures be appropriate to the needs of the people living there (Needs and Abilities, 1991). Programmes in Ireland are now more focussed on mainstream funding. The EQUAL Community initiative was established after all 15 member states of the Commission agreed to create more inclusive opportunities for jobs and address inequalities in the workplace. Under this, disability funding can be drawn down for projects which combat discrimination. The Report of the Commission on the Status of People with Disabilities (1996) undertook a review of current services for people with disabilities. It is arguably the most comprehensive study carried out since the foundation of the State and was unique in its inclusion of families and individuals living with impairments. 402 recommendations were made including the establishment of the National Disability Authority an organisation, which has become hugely influential in advocacy for people with disabilities.

The principle of 'normalization' came into prominence but was later relabelled Social Role Valorisation (SRV) (Wolfensberger, 1983). It means that the social image and

personal competencies of people with disabilities are considered a priority in any engagement with professional staff. The implications for practice shifted from drugs and segregation to enhancing the image of people with disabilities in society through participation in mainstream social occasions and in identifying personal competencies in people with disabilities and enhancing them (Wolfensberger, 1983). The 'social model' of disability shifted the emphasis from the idea of disability as personal tragedy and recognised that social factors are what restrict people with disabilities from inclusion in society (Quin, 2003).

Disability rights campaigners focus on seeking funding 'to organizations of, rather than organizations for disabled people' (Fawcett, 2000: 24). This means that interactions with people with disabilities would be based on recognition of their full citizenship and enforced through appropriate legislation and policy. This succeeded in passing the Employment Equality Act in 1998 and the innovative Equal Status Act 2001. This represents a changing attitude to people with impairments as employers and service providers are required to reasonably accommodate disabled people. The independent living movement was born primarily out of disability activism in Britain in the 1970s but did not gain momentum in Ireland until the early 1990's under the influence of rapid change on a European and global level (McGettrick, 2003). Key facets of this movement include accessible housing, community care supports, empowerment and choice. Accessible housing became a legal requirement through part M of the Building regulations under the Building Control Act 1990. It provides that all public buildings must be accessible. Part M was amended in 2000 stating that all houses built after 2001 must be visitable by people with a physical disability (Building Control Act 1990). However it is a very weak provision and relatively ignored. For the Independent Living Movement, the term access expands beyond getting into buildings but is about full inclusion and participation in society.

Independent living in Ireland is manifested in Centres for Independent Living (CILs), which developed throughout the country. A small group of people with physical and sensory impairments used EU and Fas funds to launch the scheme. The first CIL was established in Dublin in 1991. It pioneered the first Personal Assistant service in 1992 and gradually expanded to other parts of the country. It is a consumer managed service where disabled people are provided with financial support to be independent at an



individual level. Funding is based on an assessment of their needs and the cost of meeting these needs. It is also referred to as the direct payments system. Under this system, the person with a disability is provided with a sum of money, which they use to hire a personal assistant to assist them in their daily tasks (Pearson and Riddell, 2006). Central to this was freedom to choose and manage their own supports. The Government took over responsibility from the original committee in 1994. Administration and training became their primary focus with the emphasis placed on providing for basic personal care needs rather than on supporting independent living and social inclusion. Thus the original vision and meaning of this service has gradually been diluted.

In *A Strategy for Equality, Summary of the Report of the Commission on the Status of People with Disabilities (1996)*, a key policy recommendation was the need to move away from the segregation of people with disabilities towards their full inclusion and participation in mainstream society. The vision of mainstreaming became one of the main objectives of the Fianna Fail and Progressive Democrat coalition between the years of 1997 and 2006 (Quin and Redmond, 2003). It required a shift in thinking on all levels. The report *Building a Future Together* was prepared by the Establishment group for the National Disability Authority and Disability Support Services and presented to the Minister for Justice in 1998. This was pivotal in that there was no involvement from any health related department or body. One of the recommendations was that the National Disability Authority would be under the Department for Justice, Equality and Law Reform.

People with disabilities successfully demanded that disability be seen as a matter of equal opportunities and human rights rather than an issue of personal tragedy (Shakespeare, 2013). It is now recognised in the United Nations Convention on the Rights of Persons with Disabilities (2006). The general principles of Article 3 of this Convention include ‘respect for inherent dignity, individual autonomy...and independence of persons’ alongside the principles of non discrimination, inclusion in society, respect and acceptance of differences, equal opportunities, accessibility and gender equality (United Nations Convention on the Rights of Persons with Disabilities 2006). The convention has no legal powers but it exerts pressure on its members who ratify such conventions to adopt these principles into national law and policy. The Irish government signed it in 2007 but it still needs to be ratified. Article 13 of the Treaty of

Amsterdam gives power to the EU to combat discrimination on various grounds including disability. Similarly, Article 26 of the charter of Fundamental Rights of the European Union (2000) ‘recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community’. This charter was originally merely a political declaration but with the ratification of the Lisbon Treaty, it has been given legal effect. This means it is now a legal basis for challenging the validity of EU laws on human rights grounds.

The National Disability Strategy was launched in 2004 with the aim of advancing the social inclusion of people with disabilities. It set out plans to address discrimination, support them to live the life they choose and participate fully in the community. The Disability Act 2005 was passed with a view to addressing the human and civil rights of people with disabilities (National Disability Strategy 2004).

An extensive study of deinstitutional literature was carried out by the National Disability Authority (2007) and it explored a range of elements characteristic of supported living environments. Benefits included social networking and community involvement. The National Standards of Residential Services for People with Disabilities was published by the Health Information and Quality Authority (HIQA) in 2009 and updated in 2013. It outlines the rights, living standards and protection standards in services for adults with disabilities. It specifies that residential services must comply with current legislation policies and procedures for best practice with regular reviews and updates to keep abreast of changes. Regular inspections are carried out both internally and externally.

Efforts are being made to phase out larger institutions and care homes with a view to moving people out to community based settings. However, a report by the Health Service Executive (2011) *Time to Move Away from Congregated Settings* found that between 1999 and 2008, a total of 619 people with disabilities had been transferred from larger more isolated care homes to supported living settings based in the community. However, in the same time period, there were 692 reported admissions to congregated settings. This means that the numbers of people admitted to congregated settings exceeded the numbers of people transferred to community based settings.

## **2.2 Exploring disability models in practice**

Institutions were characteristically large communal living environments. It was taken as given that individuals in institutions were a ‘vulnerable’ group of people who needed care. Processes of care were arranged by ‘experts’ to be carried out by less skilled workers who were excluded from making decisions and care recipients were not consulted. They were typically understaffed and inadequately resourced. Characteristic of institutions was rigid routines with set mealtimes and bedtimes and standardised approaches to treatment of people (Tronto, 2010). Disability was viewed as a physical deviation from the ‘normal’ body/mind and as a consequence, they were unable to perform ‘normal’ tasks (Haralambos and Holborn, 2008). The ‘individual’ or ‘medical’ models are terms used to refer to the ‘medicalization’ of disability (Oliver, 2009). Much of disability related policy and provision was under the aegis of the Department of Health and this influenced how disability services were dictated. Under the medical model, the key view of disability is that it is a personal problem and that individuals must adapt to their physical and mental limitations and be supported to accept this by depending on the charitable support of others (Fawcett, 2000). People with disabilities were perceived as ‘powerless’ (Hall, 2011). They were excluded from most discussion or decision making, which was carried out by professionals. Due to limited monitoring or inspection, oppressive practices went unchecked (Braye and Preston-Shoot, 1995).

Under the traditional service model of delivery, group/care homes are the norm. Medical approaches which emphasised diagnosis and drug treatment dominated in this model and most staffing in such group homes comprised of registered nurses (McCormack, 2004). In a care home larger numbers of residents share a living space. Their bedrooms may be private but living and dining areas are communal with meals provided by caterers. The traditional service model has a hierarchical management system with senior management on the top and frontline staff at the bottom (Finnerty, 2012). Managers assume responsibility for the daily running of the agency. Care assistants are typically unqualified and tend to be viewed as subordinate to medical professionals. They engage in basic personal care and welfare tasks (McConkey and Collins, 2010). Care and welfare were subordinate to diagnosis and treatment. Routine is a feature of care homes with set mealtimes and bedtimes. All information regarding residents is

recorded and documented by professionals. Changes to legislation and policy led to a move away from care homes towards community based living.

Many Irish organisations now provide community based accommodation with small numbers of up to three or four service users living together in an average sized house. A hierarchical management structure also exists in these settings but Finnerty (2012) argues that with the social model, the role of the worker has changed and they have a more active role in supporting people with disabilities to make more informed choices, participate in the community and gain more control over their own lives. New thinking now requires staff to have various levels of qualification in social care (Lyons, 2013). Social care emphasizes person centred values and recognizes that people with disabilities can be supported to be actively involved and in control of their own lives. People with disabilities are often assigned a key worker who, using person centred planning discusses goals and aspirations with them and supports them in their efforts to achieve their goals (Killeen, 2014). People still have a number of health and care needs but rather than passively receiving medications from a trolley at a set time, they are encouraged to medicate themselves (McConkey and Collins, 2010). Similarly, disabled people are more involved in and have access to their personal records, which includes their medication, education/ day centre and their goals. Language and imagery is designed to ensure people understand what is being communicated (Forster and Iacono, 2008).

According to Emerson et al (2001), there exists a wide range of impairments and support needs within settings intended to promote independence: support to wash or dress, assistance with mobility and support with behaviours that may be distressing. Staffing is allocated based on these needs and workers must to be flexible. Day shifts may be up to 12 hours in length. The shift system operates overnight with systems of 'on call' or 'waking night' (McConkey and Collins, 2010). This is necessary with people who may be incontinent during the night or have health conditions, such as epilepsy that require regular monitoring (Forster and Iacono, 2008). On the other hand, in a house where people are more independent and have lower support needs, staff may work on a visiting basis, arriving at set times in the day to support people in particular areas, such as the morning routine or making dinner (Lynch and Lyons, 2009).

The direct payments scheme is a relatively new system in Ireland. Rather than changing the location of people with disabilities, as was the focus when transferring people from institutions to the community, current ideologies and systems are being challenged. In this system, people are called leaders and encouraged to find their own care workers within the conventional labour market (Ungerson, 2005). Workers do not complete daily notes or indeed any written records to be viewed by others. Care workers employed under this system are largely unqualified (Ungerson, 2005). Some such arrangements can be fraught with tension for both parties.

A criticism of the Independent Living Movement is that it remains exclusive to people with physical disabilities, while people with sensory and intellectual disabilities or those experiencing mental health problems have yet to participate. While people with physical disabilities are beginning to assert their rights to choice and control, people with learning disabilities generally lack confidence and are dependent on carers (Hall, 2011). This is problematic because it locates the cause of the lack of choice in the people themselves. It is the case that intellectual disability services and associated professionals have been slow to identify ways in which choice and control can be exercised among people with a wide variety of cognitive capacities (Barnes, 2012). Personal budgets can only be considered effective if the person in receipt of one is able to manage it. If someone else needs to manage it they are still dependent on another person (McLaughlin, 2009). A number of challenges may arise within the direct payments system. Allocating set hours a year means that when an urgent need arises, the leader might use up more hours than they can afford. The system does not necessarily protect against patronizing, insulting or even abusive behaviour from workers. Morris (1993) gives the example of a person who was very roughly handled by a carer who insisted that she say 'please' and 'thank you'. Leaders may be left at risk if their hired worker does not show up. Further, there are financial issues. Funding is generally not sufficient to pay a competitive wage or salary to workers as often very sparse services are offered. This makes for a very uncertain working climate for social care workers and inadequate support for people who want to be more independent and who may not have access to sufficient resources to meet their own support needs or pay a decent wage. It is likely to lack the security of a permanent job as the discretion remains entirely with the leader.

Within the disability movement, care is viewed as having rendered people with disabilities powerless and with no choice or control over defining their support needs or who meets those. It is also associated with paternalism and control by professionals. As a result 'care' has been abandoned by many within the disability movement in favour of choice and control. Similar to current social ideals, privacy, individuality and choice are prioritized over collectivism and interdependence. This exists within a neoliberal context where freedom of movement for capital, goods and services is promoted, previously state owned enterprises are privatized and citizens are given 'individual responsibility' for health and education (Steger and Roy, 2010). 'It may be no coincidence that the disability movement's stress on independence and autonomy has coincided with the resurgence of the free market and privatization' (Shakespeare, 2006: 138).

### **2.3 Contemporary debates: care versus independence**

It is necessary to explore the contrasting debates around care and independence. DSWs by definition are employed to 'support' the disabled person. In many cases intense levels of physical, social, medical and emotional support is necessary to address the high dependency levels. Care as a 'basic good' necessary for the maintenance of society and one, which all persons would lay claim has been advanced by writers such as Parks (2010) and Tronto (1993) among others. The ethics of care was popularized among feminists in the 1980s following writings by Carol Gilligan. Ethical theories focused on universal principles and the ideal of people as independent rational beings serves to overlook the significance of caring relationships in the context of dependency and vulnerability (Bowden, 2000). Traditional moral theories, which emphasize autonomy and independence are criticised for male bias. Gilligan (1982) distinguished between care ethics, which is concerned with relationships and interdependence and justice ethics, which prioritises rules and autonomy. Historically, justice principles have dominated moral thinking and has served to deny women's perspectives and the exploration of care ethics (Sherwin, 1992).

Feminine ethics recognizes the experiences and moral practices of women. They are guided by ideals of interdependence and relational connections (Gilligan, 1982). Because women are usually charged with the responsibility of caring for children, sick and older people, they see the world as a web of interdependent relationships. Noddings

(1984) believes both males and females should pursue a feminine ethic of caring. The general consensus is that ‘theories should involve models of human interaction that parallels the rich complexity of actual human relationships and should recognize the moral significance of the actual ties that bind people in their various relationships’ (Sherwin, 1992: 49). Feminist ethics encompasses all feminine principles but also includes a political perspective critiquing practices that oppress women (Sherwin, 1992).

The ethic of care has gained support for being more inclusive of people with disabilities who rely on the assistance of other people and for many it is not possible to be fully autonomous and independent (Wendell, 1996). The category in care ethics where the one cared for is more vulnerable than the one caring is typical of the traditional view of disability (Bowden, 2000). Care ethics refers to the quality of the relationship and the character of the people in the relationship. Ethically successful relationships are those that are mutually empowering, respectful and caring (Bowden, 2000).

Disability theorists distinguish between ‘the social model of disability, which recognizes that disability is created by a society which ignores or negatively responds to the requirements of a minority of its citizens, contrasting it with an ‘individual model’ which identifies the problem as one created by deficiencies or impairments of certain citizens’ (Stevens, 2008: 199). The social model represented a shift from a paternalistic view of ‘clients’ who passively received services to the perception of active citizens who could refuse or reject care services that were not to their satisfaction. Person centred language (e.g. ‘wheelchair user’) replaced disempowering terminology (e.g. ‘confined to a wheelchair’).

Disabled people challenged existing paternalistic attitudes to disability. Morris (2001) contested the oppression of disabled women based on her own experience of prejudice and discrimination. Oliver (2009) argued that it is important to distinguish between impairment and the social issue of disability. For him, impairments are physical, learning or sensory restrictions, while disability is the exclusion from society due to a lack of resources. He contended that impairment is not the main cause of the social exclusion of people with disabilities but rather the societal response to people with impairments. ‘The problem should not be located within an individual person, but rather in a disabling environment which excludes and denigrates disabled people’ (Thompson,

2001: 113). People with disabilities can be supported to have their needs met by using common resources used by all citizens rather than resorting to segregation from the community (Kendrick, 1997). Yet, this is only possible if it can be taken for granted that all community resources are accessible.

The rights based approach is driven by the disability movement (Shakespeare, 2006). Disabled people claimed they had the right to organise their own care and support rather than continue to be dependent on professionals to make decisions on their behalf. This led to a focus on empowerment, independence and the development of ‘cash for care’ systems where people with disabilities are provided with a personal fund, which they can use to purchase and manage their own services. This shift in perspective from a ‘user’ of care and support services to a consumer is congruent with arguments against welfare state dependency (Ungerson, 2000). This system is promoted as a method to increase independence as individuals have greater choice and control over services (Christensen, 2010).

Despite the drive towards independence, the care needs of people with disabilities must continue to be recognized. All people are interdependent and we are all also dependent at some stage of our lives whether due to illness or accident, when we are very young or as older frail person, so dependency is a feature of all human life and interdependence rather than independence is a more accurate description of our social world (Kittay, 1999). Shakespeare (2006) points to the reality of greater degrees of dependency for some groups of disabled people spanning longer periods of time, often over an entire lifetime. This ongoing dependency should not be dismissed and needs to be given due recognition in order for disabled people’s needs to be properly met. Souza and Ramcharam (1997: 5) point out, ‘each person has different needs...but that does not mean they have to be negative’. By focussing overtly on independence, there is an implicit suggestion that to have any form of dependency is negative. The current emphasis on independence is positive but needs to be considered in relation to all aspects of a person or it may alienate some people with more severe impairments. The drive towards independence may actually serve to exclude the group it is trying to liberate. ‘We must reconceive development, not only toward independence but toward whatever capacities are there to be developed’ (Kittay, 1999). It is important to move away from a focus on independence as if it solely defines a human being.



The rising emphasis on the social model has had a positive impact on how people with disabilities are supported (Morris, 2001). A study by Hawkins et al (2011) on DSWs in the UK using qualitative observations, semistructured interviews and documentary analysis found that staff perceptions of their role included the acknowledgement of service user autonomy by promoting independence. The importance they placed on independence meant that some workers deviated from standard risk assessment procedures in order to manage tensions in their duties. Many people with disabilities still require some level of care and this conflicts with efforts to promote their independence. The prevailing idea is that independence is the goal to be attained as if a person could get by in life without care. They are not mutually exclusive but are perceived as such within a neoliberal context where independence is valorised and dependency stigmatized. DSWs aim to empower service users, while simultaneously providing direct personal care (Windley and Chapman, 2010). It is this ambiguity about their role that creates a significant amount of stress for support workers (Hastings, 1995). This confusion is echoed in a large scale study by McConkey and Collins (2010) on 245 staff in disability support services across the UK. It was found that the level of importance staff placed on independence and inclusion varied greatly across the settings and was largely dependent on the leadership, training and resources.

Feminist ethics is concerned with ideals around interdependence and relationship (Hesse-Biber, 2011). Typically in feminist care ethics, the person receiving care is more vulnerable than the person providing the care (Bowden, 2000). Feminists largely argue that care is necessary and challenge the oppression of women in caring roles. This contrasts sharply with disability activists' fight for rights based approaches appealing to difference rather than disability. However, Shakespeare (2013) recognises that impairment still exists and is not just socially constructed. Thus people require care, support or assistance based on their level of need. Arguably this is the ideal but the reality largely reflects a huge chasm between opposing viewpoints. This is central to identifying the tensions between the rhetoric of independence and the reality of DSWs role in situations of high levels of dependency.

## **2.4 The politics of language in disability**

The way in which an idea is communicated to others will largely influence how it is interpreted (Dieringer and Porretta, 2013). Labels can be interpreted on a denotative

level i.e. the literal meaning and on a connotative level i.e. the implied and subjective meanings drawn from the label (Milington and Leierer, 1996). The words 'fool' and 'idiot' were among the earliest terms for a person with an intellectual disability and are still used today to infer that a person is lacking in common sense (McCormack, 2004). Such language had a stigmatizing effect on the person affixed with such labels as it created a sense of 'other' in that they would never be like the 'normal' population whom they were segregated from. Words such as 'lunatic', 'moron' and 'imbecile' were used in official reports and Victorian legislation (Mc Laughlin, 2009). They are no longer used in this context but are now popular among adolescents to berate one another. Terms, such 'feeble minded' and 'defective' appear more offensive and did not enter into modern usage. In the mid 20<sup>th</sup> century the term 'mentally handicapped' came into common usage but was replaced in the 1990s with the term 'intellectual disability' and this remains largely in use in government documents today (McDonnell, 2009).

Language used in relation to people with intellectual disabilities has become better intentioned as it evolved with moves towards more humane treatment of people with intellectual disabilities. However, McCormack (2004) argues that there emerged a suggestion that people with intellectual disabilities are objects of pity who will remain eternally childlike and a burden on charity. Thus, while they may no longer have been housed in asylums, they still continued to be treated as subordinates where their rights were suppressed. People with intellectual disabilities received education and services in separate settings labelled as 'special' (McCormack, 2004). The word 'special' commonly means that something is better than usual but when it is used in relation to people with disabilities who have 'special needs' it suddenly implies something less than desirable (McCormack, 2004). The word 'special' only developed a negative connotation after it came to be associated with people with disabilities thus suggesting that there exists an underlying negative attitude towards disability.

The term 'client' can be considered positive as it usually refers to an active citizen using the services of a solicitor or other professional company. It came into use in the social care in the 1970s and is still the most popular term to describe the social work relationship (McLaughlin, 2009). In the UK it was challenged as it was constructed as someone needing help because they lack the necessary capacity or abilities to help themselves. It is only after the term began to be used in relation to people with

disabilities it developed negative connotations (McLaughlin, 2009). It came to be viewed as a disempowering term reflecting their passivity and dependency on the social care worker despite the fact that this was not the original intention for the word (McLaughlin, 2009). Because actions and attitudes did not change, the word developed a new meaning.

In an increasingly individualistic society, terms such as ‘client’, ‘customer’ and ‘consumer’ came into use in relation to people with intellectual disabilities. Such words are used in a commercial context where a person is purchasing goods or a service. It assumes a commercial transaction and a capacity to weigh up costs and quality before a purchase. ‘Consumer’ also connotes rights i.e. ‘consumer rights’ (McLaughlin, 2009). In this context it fits with the broader shift towards privatization and marketization of services and the responsabilization of the individual and the requirement to exercise choice and take control over services purchased to meet needs. This changing perception gave rise to the direct payments system. These terms suggest that care and welfare are commodities to be bought and sold, managed by the person who needed them (McDonald, 2006).

The term ‘service user’ is commonly used today by social care professionals to refer to the group of people with intellectual disability with whom they work. McLaughlin (2009) is critical of this term as it creates a sense of homogeneity, where they are assumed to be similar to one another with just one aspect of their identity (the one they have in common i.e. the fact that they are all users of a particular service) given greater privilege and their differences are not celebrated. A further criticism is that the term ‘service user’ actually excludes people who are not using a service whether they are denied it or refuse to use it because of the fear of stigmatization (McLaughlin, 2009).

Despite the many changes in terminology, it can be argued that the language used in relation to disability continues to create a discourse barrier between those with and without a disability (Race, 2002). It implies that people with a disability are still ‘different’ and thus require a label to communicate this. Race (2002) is critical of attributing labels to people with disabilities by perceived ‘experts’. Llewellyn and McConnell, (2002: 316) observed that ‘the learning disabilities label continues to evoke a stereotyped response’. ‘People with disabilities do not want to be pitied nor do they want their disabilities to be dismissed of as little importance’ (A Strategy for Equality,

1996). Race (2002) argues that the only meaningful label that should be attributed to a person with a disability is their name.

Definitions of disability influence official understanding and any policies affecting disabled people. Terms used in existing legislation to define disability include ‘malfunction’, ‘malformation’, ‘disfigurement’, ‘illness’ and ‘disease’. According to section 2(1) of the Disability Act 2005, disability is defined as ‘a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State by reason of an enduring physical, sensory, mental or intellectual impairment’. This terminology suggests that despite the dramatic social changes, there remains an underlying attitude that issues related to disability lie solely with the person, rather than with a disabling society. While impairment does actually exist, people are further restricted in the absence of supports to enhance their capacity. A new legal framework is currently being introduced to redefine intellectual disability (Killeen, 2014). The only existing definition for people with intellectual disability, mental health, dementia and acquired brain injury is in the Regulation of Lunacy (Ireland) Act 1871. This new legislation may signal a move towards empowering people with disabilities to have control over their own lives (O’Brien, 2013).

The language we use when referring to people with disabilities still represents a power imbalance, for example, distinguishing between ‘staff’ and ‘service users’ or people with and without a disability. Labels such as ‘client’ or ‘service user’ are not descriptive of a person but of a relationship (McLaughlin, 2009). Morris (1991) argues that while it is essential to move away from disabling language, services may not change much at all. Positive terms can be used to describe what continue to be oppressive practices. She refers to a specific service, which claimed to be empowering service users but actually people's labour was used to create items for sale in the organization's craft shop. If they refused, they were seen as ‘being difficult’. Another setting was smaller and community based but routines continued to suit the staff. When service users sought freedom to choose their own bedtimes or to go out, it was viewed as challenging behaviour. She also observes that medical approaches continued to be used in cases that were not necessarily ‘medical’, for example using sedating medications to manage challenging behaviours rather than addressing the source of these behaviours. It is clear from these examples that it is essential not just to change language but actions and practice.

## **Conclusion**

This chapter has discussed a historical overview of approaches to addressing disability and appraised the medical and social models. Positive developments have been made but there are also a number of concerns that need to be addressed. The medical model seeks to ‘treat’ and ‘cure’ disability as though it were an illness. The social model sought to challenge oppression and discrimination against people with disabilities. Disability theorists such as Morris (2001) and Shakespeare (2006) seek to combine an understanding of the reality of disability whereby capabilities are encouraged but care needs are not dismissed. The concept of care has moved between positive and negative connotations. Tension still exists between the two extreme strands of traditional care and protection and modern independent ideologies. Therefore, the purpose of the next chapter is to explore key debates around disability support work in greater detail.

## **Chapter 3: Factors Affecting disability support work**

### **Introduction**

The concepts of ‘care’ and ‘support’ have become increasingly contentious topics and are the subject of fierce debate among theorists, in particular feminist activists and scholars. This chapter will now explore key tensions experienced by Disability Support Workers in their role. As women entered the paid labour force, they tended to occupy positions which drew on such supposedly ‘caring’ characteristics. Thus, the first section of this chapter questions the gendered nature of disability support work. The second section explores the concept of care as a labour process drawing comparisons with industrialization. The third and fourth section examines the experience of disability support workers focussing on the bodily aspect as physical labour and the impact of emotional labour. The final section addresses the need to provide the worker with appropriate support.

### **3.1 Gender**

Concern arose among feminists that institutionalized social practices for generations have led to oppression and subordination for women and the privileging of men in the private and public sphere. Care work holds a fragile status as a profession. It is not clear whether this is because it is care work or because it is work carried out by women or as is likely, a combination of both (Cameron, 2007). Etzioni (1969) suggested that occupational groups such as nurses and social care workers should be categorised as ‘semi-professions’ because their work is more ‘applied’ than the more theoretically informed work of the professions. ‘Caring is seen as what women would do for their families without payment in any case’ (Abbot and Wallace, 1990: 5).

Women are viewed as naturally maternal and selfless and thus more suited to caring roles. This idea of selflessness is reflected in a study by Prain et al (2012) on eight Australian DSWs who work with adults with congenital deaf-blindness in supported accommodation settings. It was found following an analysis of qualitative interviews that staff place a strong emphasis on the physical, material and emotional well-being of service users. Further, Windley and Chapman (2010) found in their study of support workers with adults with intellectual disabilities that staff felt stressed when expected to

do anything that they perceived as having a negative impact on service users' well-being. This stress emerged as a result of conflict between their beliefs and the demands of the service. It was recommended that more on site supervision to provide leadership be provided.

Care provision is considered a subordinate position, which is dominated by females. 83.6% of workers in caring, leisure and other services in Ireland are female (Central Statistics Office, 2013). Nurses remain subordinated to doctors and other male professionals in the hierarchical management system within medicine (Pearson et al. 2005). Women earn less because they are more likely to work in female dominated jobs, which pay less (Burns and Kinder, 2011). Critics suggest that they choose lower paying jobs for pleasant conditions, the opportunity to serve others, flexible hours and 'easy work' (Burns and Kinder, 2011). But actually 'female' jobs do not offer such benefits as flexibility and are more likely to involve 'working with different clients, cleaning others' dirt, mindless repetition and low autonomy' (Burns and Kinder 2011: 65) Wages are not linked to undesirable work because those in lower status positions in the social hierarchy do the low status jobs and are often not in a position to complain. It is also untrue that women choose these jobs but rather that when they apply for others, men are more likely to be offered the position (Burns and Kinder 2011).

It has been argued that care is feminine in four ways: It characterizes that which is feminine; the prevalent division of labour assigns care to women; female identity is associated with connection and women endorse an ethic of care more than men (Bubeck, 1995, pp.159-170). Witz (1992) suggests that there are two key ways in which women remain in an inferior position to men. The first is a gendered exclusionary strategy, where women have limited access to 'male' environments. In the past this may have been education, preventing them from getting qualifications. The second is a gendered demarcatory strategy where women are restricted to a specific sphere, such as nursing or midwifery. There is a long held assumption that women are suited to caring roles as they are instinctively maternal and have a natural ability and desire to care for other people (Kittay, 2001). 'Women are not usually thanked for their nurturing, because it is accepted as natural to them and therefore not recognised as work. They are, however, blamed and often punished if they fail to deliver' (Sherwin, 1992: 16).

According to Meyers (2003), women are unlikely to contest the expectation of them to work in caring roles as they find it satisfying. Houston (1990) argues that just because women may be willing to serve others, it should not be assumed that they are passive. Tong (1998) notes that physicians may be very attentive to their patients but this does not necessarily mean that they are behaving in a moral manner because they must truly care about their patients. This suggests that to care means to be attuned to other people's realities and to have an active concern for the wellbeing of others (Carse, 1995). Blum (1980) distinguishes between conscientiousness, where people work hard to fulfil responsibilities and kindness, where people selflessly volunteer to do something that is above and beyond their expected duties. 'The ethos associated with the ethic of care also calls on a conception of context-sensitive and emotionally-engaged moral deliberations that resists abstract formulations of moral problems' (Bowden, 2000: 39).

### **3.2 Disability support work as a labour process**

The concept of DSW as a labour process emerged frequently in the literature (Dustin, 2007; Ritzer, 2000; Leidner, 1993) and it was necessary to explore this in greater depth. Emile Durkheim (1858-1917) points out that with industrialization, solidarity metamorphosed from interdependence based on moral agreement to functional dependence on one another to reach goals (McDonald, 2009). Traditional divisions of labour meant that the work process was organised so that each stage in the production process was completed before moving on to the next. Each worker was skilled in a large number of areas. Work has now become more specialized and inequality of rights has become more apparent, thus leading to a sense of isolation and meaninglessness. He calls this anomie. Anomie may occur in care work because care was not traditionally viewed as 'paid work' but something women did naturally. Now, care is provided within a formalized, 'work structure'. A clash can occur between the reality of the job and ideas of what caring is meant to be like. Employers often work off the assumption that care work comes easily to women so they do not need any training or qualifications and therefore do not need to be paid a competitive wage (Ritzer, 2000).

Speaking from a Marxist perspective, Ritzer (2000) asserts that work is no longer an expression of human potential. Managers who are in the minority do all of the 'head work' while the workers do the 'hand work'. In a similar vein care has become commodified in that it is viewed as a process, which can be bought and sold (Barker,



2003). This has served to contribute to the repetitive, monotonous tasks that Ariely (2012) calls sisyphic conditions, based on the myth about Sisyphus, a Greek god who was punished to spend eternity repetitively pushing a stone up a hill. Ritzer (2000) contends that a key flaw within organizations is the assumption that people purely work for a wage, yet the main motives for work are not only economic but also personal satisfaction and social status, companionship and security (O'Donnell, 1994: 147).

There are similarities between systems in care organizations and Taylorism and Fordism, despite the fact that these originated in relation to car manufacturing. Taylorism is a process introduced by Harry Braverman where the discretion of the worker is transferred to management and tasks are simplified (McNally, 2010). He also introduced technology as a means of manufacturing large quantities more cheaply, which led to a deskilling of the labour force. Henry Ford expanded on this to include the fragmentation and simplification of tasks. He discovered that using a moving assembly line reduced wasted time and therefore increased productivity but also led to lower quality of products (Edgell, 2012). As care has become increasingly commodified, its simplification has also led to devaluation of the work and deskilling of care work tasks. Typical care related tasks are focussed around supporting people with showering, shaving, dressing, taking medications and with incontinence. Time is allocated within which these tasks must be completed without regard for the person to be able work at their own pace. This implies that care has little value and the people are mere units in getting the task done.

It is not necessarily possible to physically break down care into smaller tasks but the idea of care can be fragmented in the social psyche and presented as unskilled. This can then be used to justify using cheap labour and providing little or no training for staff. Share (2013: 3) notes that social care remains undefined and this suits governments and agencies 'as it helps keep salary and career structures vague'. Care is devalued through a 'patriarchal bias' that it is women's work (Edgell, 2010: 65). There is a tendency to devalue emotional, social and caring skills because they are viewed as inherently female and therefore do not need to be formally taught (Davies and Rosser, 1986). Complex and interactive skills such as listening, communication, coordination and emotional management are crucial to success in the service sector but difficult to measure and evaluate (Edgell, 2012). As a result, they are detached from physical work with greater

importance placed on observable tasks. Goffman (1959: 41) considers how nurses are perceived to be 'wasting time' 'unless they are darting about doing some visible things, such as administering hypodermics'. In the same way, this performance is expected of care workers in that they should be seen cleaning or providing personal care rather than taking the time to build relationships with the people they support.

The introduction of machinery in production meant that less people needed to be employed. In care work, certain aids such as hoists are necessary to do the work. However, technological advances are now pioneering the use of robots to provide care. An example of this is a form of human washing machine, which is described as follows:

To operate the machine, the user sits in a chair that rolls backwards into place. The machine then encloses the bather like a clamshell, forming a tub with the bather's head protruding from the top. The machine delivers a dollop of body wash and provides heat and bubbling action. Hair washing and drying the bather's body is done by hand (Parks, 2010: 103).

It is difficult to imagine how a person could retain their dignity when using such a machine. The machine does not necessarily eliminate the need for care staff as assistance would be needed to help the user on and off the seat, wash their hair, dry and dress them. On a purely practical level, the act of washing a person's body is probably the quickest and easiest part of the whole bathing routine that the expense involved in purchasing, running and maintaining these baths appears unjustified. Other technologies include a speaking robot with cameras that can move around to 'check on' people (Brooke, 2004) and an exoskeletal 'robot suit' that will enable people to walk (Ponsford, 2013).

The fact that these are being developed suggests that care is perceived to be of little value if the person doing the care can be replaced by a robot. Further, it ignores the need for basic human interaction. Carers need to recognize service users as people and not just as mere 'bodies' (Tong, 1998). Sparrow and Sparrow (2006) believe that the introduction of robots would mean a decrease of staff. Therefore the already limited social contact afforded to services users through workers would now be even further reduced. Interestingly, Mullin (2011) contends that such developments could be beneficial; assuming the company and social contact is not compromised. Care workers could be protected from physically demanding work and care recipients can avoid some of the shame associated with bodily need and public nudity

### **3.2.1 The role of managers**

It is necessary to consider the role of managers, particularly those in direct line management of DSWs because how managers engage with their staff will impact on staff experiences in their working environment and the quality of service delivery. The typical management structure of health and social care organisations is hierarchical in nature with an individual manager or committee at the top responsible for the overall running of the organisation, general managers who have more concentrated responsibility for a particular portion of the services, care or line managers, who have a very specific responsibility for one or two houses, the staff who work there and the service users who live there. Managers of care and support settings are usually qualified in social work or nursing (Taylor et al 2013).

Administrative tasks that managers are responsible for include designing rotas and arranging cover; creating and maintaining person centred plans and files for service users; scheduling and attending service user review meetings; requesting resources and writing up progress reports. They also have an element of human resource management in how they manage their staff. In this regard, responsibilities include allocating key workers and delegating responsibility to staff. According to Smyth (1996), management style should be person centred and value the staff-service user relationship. Teamwork and flexibility should be encouraged and staff accountability recognised. Whitely et al (1996) stress the importance of affording recognition to staff for the contributions they make. This can take place in structured supervision meetings or informally. Line managers are positioned between staff and area managers. They are considered to be the mediators between 'expert' knowledge and allocation of resources (Parton, 1994). Thus in DSW, the manager influences the experience of the job for staff as they are responsible for supervision and support of staff.

### **3.3 The body**

Up until recently, the body was not considered in sociology. Anthropologists saw the body as a surface on which culture is inscribed e.g. clothing, tattoos and piercings but a distant stance was taken when discussing the body rather than exploring it as it is lived (Williams and Bendelow, 1998). The physicality that is part of disability support work cannot be ignored. At a most basic level, workers are required to undertake training in

moving and handling. Toynbee (2003) notes how every personal care task becomes an act of physical labour and describes her experience of bathing a woman:

I could see why no one liked baths. In the bathroom, once she was naked, I would sit her on the chair attached to a hoist and winch her up, swing her over the bath and winch her down into the warm water full of bubble bath, wash her all over and winch her out again. However kindly we did it, it was not much fun and certainly not dignified.

The relationship between the worker and service user is often fraught with tensions between professional duty and personal bonds. Kittay (1999) points out that workers have to fulfil their obligations even when it is at a substantial cost to themselves, for example staying up at night with the person. Physical and emotional stamina are often stretched to the limit in these environments. However, she argues that the worker should not have to sacrifice all of themselves in the caring relationship.

It does make sense for me to relinquish a portion of my autonomy...Yet this does not mean that I must acquiesce to the 'feminine' virtues of self-effacing self sacrifice. It means that we need a reconfiguration of how reciprocation comes to be possible in the case of dependency work (Kittay, 1999: 180).

Hamington (2004) argues that the body is central to approaching care based ethics. Caring knowledge is unique in that habits are stored in the body. The 'caring imagination' is where a person instinctively knows what to do. This kinaesthetic memory may be as simple as standing with your legs apart, forming a wide base while supporting a person to transfer from their wheelchair to their bed. There is a connection in that the worker is aware of how they must use their own body in order to support the body of the service user. Merleau - Ponty (1958) observed a deeper level of empathy in that we have a certain understanding of other people's bodies. The body can capture the subtle emotions in others that are difficult to express verbally. Bodily contact such as a handshake or kiss is not so much articulated as experienced.

Care is often referred to in relation to love and emotionality, while its reality as bodily work is often down-played (Twigg, 2004). Care workers deal with bodily contact that is not normal between strangers. It is interesting that usually nudity is associated with intimacy in the private sphere, while public nudity is connected with embarrassment or shame. These conventions are breached in settings for people with disabilities (Wendell, 1996). People with disabilities are often so used to numerous carers that their sense of

shame diminishes. In relation to nurses in a medical setting, Lawlor (1991) suggests that there are three implicit rules that the patient must follow when body care is taking place: *accept that they are fully dependent; comply with the nurse and behave appropriately* when body care is taking place. In some cases, limited understanding means that people with disabilities are less likely to adhere to these rules, which are arguably very value laden and therefore, providing care can be challenging. Haralambos and Holborn (2008) identify a series of contextors in medical settings to ensure that nudity between strangers is handled effectively. The nurse wears a uniform as a symbolic statement about their relationship; behaves in a professional manner to depersonalize the situation; carries out the care in private to minimize shame and avoids discussing the more embarrassing aspects of the care.

Medical and care professionals have privileged access to patients' bodies. 'The ritual of washing patients is to maintain a semblance of order in a highly disordered environment by maintaining the boundary between cleanliness and dirtiness' (Lupton, 1998: 127). Because care work is perceived as 'dirty work', it is difficult to talk about with outsiders as it is seen as socially unacceptable. DSWs often have no uniform because they are in the service user's home. In addition, the ethos of the employing agency is likely to be built on expectations of informality. This means that not only is it more difficult to manage 'dirt' but workers have no protection against infection (Royal College of Nursing, 2013). It is worth considering that people with intellectual disabilities may find the uniform easier to understand because they provide the necessary distance to minimize shame about nudity.

When considering the body, we should not only focus on the patient but also on the experience of those who care for them (Lupton, 1998). Fine (2005) argues that the body of the caregiver needs to be given due recognition, rather than seeing it purely in terms of its contact with the person receiving care. It is worth commenting that while DSWs care for service users' bodies, they often neglect their own (Pittman, 2012). Irregular working hours make it difficult to maintain a healthy balanced diet with regular exercise (Geliebter et al, 2000). Care workers usually rely heavily on caffeine to keep alert during long shifts and generally eat cheap, filling foods that are quick to prepare but are lacking in nutritional value (Persson and Martensson, 2006). Vyas et al (2012) analysed 34 studies involving over 2 million people and found that shift work is linked to an

increased risk of strokes and heart attacks. This is significant because workers are relying on their body to be healthy in order to do the work more so than in other jobs. A study by Scott and McClure-Cassie (2007) examines the psychological stress and physical strain experienced by personal care assistants in an assisted living facility, which contains a general housing area and more specialised units for people with dementia. The findings showed that the staff who worked with people with dementia and other memory related disorders suffered from more stress in relation to interpersonal conflicts and work constraints but there were no differences in relation to physical workloads or strain in comparison to staff working in a similar role but not specifically with people with dementia.

### **3.4 Emotional labour**

Classical economics and sociology have perceived humans as rational beings. The dependency and vulnerability of people has rarely been considered seriously (Badgett and Folbre, 1999). This has been challenged by care feminists who argue that citizenship should be redefined to respect emotionality, dependency and interdependency (Held, 1995). The concept of care as emotional labour was developed by Twigg (2000b). In addition to being physically able, DSWs also need ‘emotional stamina’ (Hochschild, 1983: 98). Lynch and Lyons (2009) contend that care is work despite social attitudes to the contrary. It demands empathy, understanding and attentiveness at an emotional level, not required in other professions. ‘As a job requirement or expectation, care giving is emotionally demanding and often performed in unequal relationships in which recipients’ needs are primary and providers are disadvantaged’ (Wharton, 2009: 154). There is an emotional strain on workers who are frequently at the receiving end of flashes of temper and challenging behaviour from service users and indeed momentary losses of temper from colleagues (Toynbee, 2003).

People in caring professions ‘are expected to feel concern, to empathise and yet to avoid too much liking or disliking’ (Hochschild, 1983: 150). Workers spend long periods of time with the people they support and become ‘fond’ of them (Toynbee, 2003). On the other hand the worker may face conflicts if they dislike the service user. ‘The ethical responsibility of the one caring is to look clear-eyed on what is happening to her ideal and how well she is meeting it. She sees herself, perhaps, as caring lovingly. But perhaps [the service user] is cantankerous, ungrateful, rude and even dirty. She sees

herself becoming impatient, grouchy, tired and filled with self pity' (Noddings, 1984: 100). Interactive service workers who are forced to express certain emotions, such as friendliness and disguise their true feelings experience alienation (Edgell, 2012).

In any job where emotional labour is expected 'it is often part of an individual's job to accept uneven exchanges to be treated with disrespect or anger by a client, all the while closeting into fantasy the anger one would like to respond with' (Hochschild, 1983, pp. 85-86). In social care this imbalance is even greater, with service users frequently exhibiting challenging behaviours towards staff. Social care practitioners often have to respond to a situation in the moment making the most informed choice they can and then work with the consequences of that decision afterwards (Lyons, 2013).

Disability support can be particularly challenging and stressful. As a result workers may develop strategies to manage this stress such as becoming less emotionally involved with the people they support and focusing instead on completing tasks (Statham, 2004). 'Emotional labour involves close attention to another, interpreting and responding to their needs; and to work properly, it requires staff to go beyond a mere formulaic response and give something of themselves' (Twigg, 2000b: 172). Key elements to ensure positive relationships form include: talking and listening rather than silently carrying out tasks; emotional attachment rather than detachment; responding to the uniqueness of individuals while still respecting the moral imperative to treat them equally; spending time building trust rather than prioritizing rules and schedules (Stone, 2000).

Reuzel et al. (2013) analysed recordings of social interactions between staff members and disabled people. It was found that the staff tended to ask more direct questions and dominated the conversation slightly more. The disabled people, on the other hand, provided extended responses, which helped to maintain more natural dialogue. Both parties faced difficulties establishing collaborative dialogues, though this challenge was lessened by forming strong relationships. Equality in conversations was an indicator of a positive professional relationship. Gibson et al. (2009) conducted a qualitative study that explored the relationships between disabled ventilator users and their personal support workers in supported housing environments in Canada. The participants agreed that they adhered to the philosophies of independent living. However, how they understood and enacted it varied considerably. There was a conflict in their

interpretations of their role between the task oriented aspects of the work and interpersonal aspects of care, respect and mutuality. It was discussed how a conceptualisation of consumer-directed personal assistance can be elaborated to accommodate ideals of 'care' while retaining the core tenets of the independent living philosophy.

Williams et al. (2009) used video material to analyse interactions between people with learning difficulties and personal assistants. It was found that difficult tasks such as giving advice were adapted by staff to be acceptable for people with learning difficulties. Successful interactions were built on sensitivity to the wishes of the person, on a moment by moment basis. Both parties coordinated their body language, humour and timing to demonstrate a close and friendly relationship, which maintained professionalism. In a study by Forster and Iacono (2008) the nature of interactions between DSWs and the people they support who all have profound intellectual disabilities was analysed through qualitative interviews with 3 DSWs. It emerged that DSWs opted for communicating in the preferred style of the person they support despite this sometimes conflicting with the policy and preferred practice of the organisation. Age-appropriateness and touch were 2 key aspects of communication that tended to be conflicted in this regard. Disability Support Workers that staff placed a high emphasis on taking the time to build relationships with service users. They contended that it cannot be formally taught but can only be achieved through spending time with individuals.

Kittay (1999) recognizes the fragile relationship between what she terms the 'dependency worker' and their 'charge' for whom they are responsible. This raises the question of what measures are in place to support and protect both parties to the relationship. Rather than blaming workers, Toynebee (2003) in her observations of a nursing home noted how the staff never got angry with residents but insensitive treatment occurred simply because they had so much work to do with limited time to do it. Every task from washing and dressing to making breakfast with each person's preferences took time and made it difficult to continuously present an air of relaxed friendliness whilst rushing about to get the work completed. There was seldom time to sit and chat with residents and she noted that sometimes workers simply had to harden their hearts passing residents who called out to them while they ran to attend to another



person. DSWs increasingly find themselves in similarly charged situations as there are continuous cuts to resources and budgets.

### **3.5 Supporting the worker**

This section will address issues of staffing, stress and burnout. These are necessary for consideration when providing support and supervision to the worker. Staffing ratios are largely inappropriate in both congregated and community settings (Health Service Executive, 2011). On average, there is 1 staff to every 2.3 service users during the day and this drastically decreases to a ratio of 1:6 at night. A specific unit for 15 people with severe disabilities is highlighted in the report because at any given time there are only 3 staff members but for large portions of the day, there are only 2 on duty to carry out daily tasks, such as washing and dressing service users (Health Service Executive, 2011). An increased emotional burden means that workers are at a greater risk of stress and burnout. Burnout may be defined as ‘a chronic state of mental, physical and emotional distress resulting from prolonged exposure to work demands and one’s subsequent response to the organisation, tasks, colleagues and clients’ (Bui et al. 2011: 461). These conditions are usually more heightened and frequent in disability support work. Burnout is more likely in professions with intense interpersonal contact in an overloaded work environment (Lorenz et al. 2010). According to Maslach and Jackson (1996), burnout consists of emotional exhaustion, depersonalization and reduction in personal accomplishment. Burnout affects the health and emotional well-being of professionals and will inadvertently have a negative impact on the people they support (Xie, Wang and Chen, 2011). Professionals are at an increased risk of burnout as they may be traumatized by the experiences recounted by the people they support (Sprang et al. 2010).

People are moral as well as economic beings (Sayer, 2007). This is why it is important to provide support for workers that they may thrive in the workplace. ‘Just as we have required care to survive and thrive, so we need to provide conditions that allow others - including those who do the work of caring - to survive and thrive’ (Kittay, 1997: 233). ‘Caring is a practice that affects both the person receiving care and those providing it’ (Kittay et al. 2005: 444). Therefore an ethic of care must also include caring for the carer. DSWs need to be valued as autonomous individuals who meet real needs in a dignified, respectful manner (Mullin, 2011) rather than an extra body to simply ‘get the

job done'. A study by Salami (2011) showed that positive social support reduced the likelihood of stress and burnout among professionals. This is supported by Gandi et al. (2011), who showed that that lack of social support, lack of control in the job and high demands lead to burnout.

'It is not uncommon for social care practitioners to fail to receive formal supervision on a regular basis, to receive verbal and sometimes physical abuse from service users, to work in under-resourced areas and to work unsocial hours' (Lalor and Share, 2013). In a situation where workers do not receive support from management or other workers, they may resort to doing whatever works, such as bribing service users. Speaking about the possibility of abusing one's power, Pitonyak (2005: 6) observes that 'the very few things that they enjoy are used contingently to reinforce compliance'. These criticisms fail to account for the fact that workers may make decisions out of desperation rather than due to a desire for control. 'There is still a feeling that [care] work is vocational, suggesting a selfless dedication to duty and putting the needs of others first' (Abbott and Wallace, 1990: 1). This idea can be used to ignore the needs of the worker and offer them infrequent but weak congratulations for doing work that others 'couldn't do'.

The experience of the worker will have an impact on that of the service user but after negative experiences, workers are more likely to resign than contest the source of the issues (Edgell, 2012). However, this leaves service users to cope with the uncertainty of high turnover rates, which is why it is important to provide support for staff. Support is not just about staff teams discussing service users' needs but also offering them an opportunity to discuss particular situations that they may have found troubling and theoretical perspectives surrounding this (Barnes, 2012). This would contribute to the collective well being of service users and staff alike in the agency. Ariely (2012) suggests that interesting and challenging work coupled with acknowledgement and recognition enhances engagement and work productivity.

Staff need to discuss fears and concerns in a safe, non-judgemental environment. It is important for workers to increase their self-awareness both in theory and in practice (Murray and O' Doherty, 2001). Professionals rely on authority figures for learning, feedback and external evaluation but gradually develop to be able make internal evaluations integrating theory with experience (Gibson, et al. 2010). Supervision and reflective practice are necessary in the workplace to ensure workers not only cope in the

job but develop and grow. The need for supervision does not reflect a form of weakness in the worker. It is natural for human beings to make mistakes so we need to review what we do, how we do it and evaluate its impact and outcomes (Moss, 2008: 32). Through reflection ‘we can gain new insight into ourselves and our practice and identify ways in which we can develop to our full potential both personally and professionally’ (Healy and Spencer, 2008: 22). DSWs need to be provided with opportunities to debrief, reflect and learn so they can understand and grow in their role, which will have a positive impact on the people they support.

### **Conclusion**

To conclude, it has been shown that women remain marginally positioned in terms of employment prospects and are still the subject of expectations to willingly and selflessly and provide care. The physicality and emotional element of the work are largely overlooked when considering work processes. Constant changes at an ideological level mean constant amendments at a policy level. It is then the responsibility of DSWs to continuously adapt and attempt to implement these changes. The next chapter will explore the methodological approaches used to develop a more in-depth understanding of the experience of disability support workers.

## **Chapter 4: Research design and methodology**

### **Introduction**

This study is concerned with exploring the experience of the disability support worker in Ireland. The literature review provided a valuable insight but some elements were unanswerable without stepping out and gaining the views of the people who work in the field on a daily basis. This chapter describes my overall approach to this research study; the choice of qualitative research, the theoretical frameworks used to examine the data, the instruments, the sampling and data analysis approach.

### **4.1 Statement of research questions**

The key questions which drove this research are as follows:

1. How do disability support workers interpret their role and construct their daily experiences in their working environment?
2. What are the challenges experienced by disability support workers and how are they supported at an organisational level?
3. What is the current legal and policy context in which disability support workers operate?
4. How can relevant theoretical perspectives be used to gain a greater understanding of disability support work?

### **4.2 Research philosophy**

This study draws on ideas from critical theory, feminist theories and disability theories. Critical theory is concerned with empowering people to go beyond constraints placed on them by race, gender and class (Creswell, 2013). In this philosophical approach, researchers explore the historical and ideological forces that have influenced the creation of social barriers and constraints. Through qualitative interviews, it was possible to identify key challenges and tensions DSWs face at the interface between discourses of independence and primary care as well as insights into how these can be resolved in the context of the barriers and constraints faced by people with disabilities.

Disability theorists use a disability interpretive lens where disability is viewed as difference rather than a defect and they emphasise how these differences are used as a rationale for exclusion. Instead of casting disability as an individual deficit, disability theorists recognise it as a natural form of human variation better understood as the results of an interplay between the individual and society and through analysing social, political, cultural and historical frameworks (Oliver, 2009). The emphasis on the distinction between impairments (functional limitations) and disability (social oppression) is the hallmark of the strong social model of disability. A central concern of the social model is the inequalities experienced by people with disabilities and the ways in which cultural values, assumptions and ideas about difference and the practical consequences of these can be disabling (Gabel and O'Connor, 2009). Debates about the social model appear to be in flux with Shakespeare (2006) among others highlighting the issue of impairment, the impairment/ disability dualism and the issue of identity. A core tenet of this approach is the concern with inequality and a challenge to the medical model, which seeks to diagnose and treat, viewing impairments as a personal condition (Toolan, 2013).

Adopting this perspective influences the focus of research in the field, language use, data collection methods, interpretation and presentation of findings. Disability researchers have focused on mechanisms of exclusion and marginalisation. An exploration of how the DSW experiences and interprets their role acknowledges the key part they play in the lives of people with disabilities. Practitioners in the field are being reframed from 'carers' to titles, such as 'disability support worker', which seek to reflect current policy commitments to supporting people to live independently rather than the treatment/ care model. While people with disabilities have challenged notions of 'care' as oppressive and inimical to independence, there is an increasing recognition that justice for care/support workers does not mean ignoring the rights of disabled people to have a voice in how services are designed and delivered and in what they themselves need.

Feminist theory is another branch of critical theory and has crossovers with disability theory in that both seek to make visible and challenge inequalities and seek liberation for oppressed groups, in this case women. Feminists question the role of gender in shaping social consciousness and seek to challenge inequality and the distorted

perception of women. The disability sector is largely dominated by women. 83.6% of workers in caring, leisure and other services are female (Central Statistics Office, 2013). For this reason, it was pertinent to draw on feminist perspectives to study the experience of the DSW. In feminist research, collaborative non-exploitative relationships are formed with the researcher placed in the research to avoid objectification and to carry out research that is transformative (Creswell, 2013).

Feminists and disability activists are critical of the positivist approach to knowledge on the basis that knowledge is constructed in specific social and historical contexts, through relationships and cannot be viewed as value free. The particular constraints and inequalities shaping the lives of disabled people and women were largely excluded from mainstream research. Feminist epistemology is largely based on Marxist and Hegelian theories which argue that an individual's understanding of the social world is shaped by their daily activities and lived experiences (Garland-Thompson, 2011). Women dominate the field of disability support work and their perspective is important to understand how they interpret their role in a context where policy is changing at a rapid rate. Women's identity in our society is shaped significantly by the moral imperative to be caring and how this in turn shapes their public role as DSW's and the tensions it raises in relation to choice and control are considerable. While men's identity is less influenced by discourses of caring, men are employed as DSW's and thus, their views are also included in this research.

### **4.3 Research approach**

The purpose of qualitative research is to develop an understanding of the motivations for human behaviour and explore the meanings people attribute to their world as these influence their actions (Henn et al. 2006). The research is carried out in real life situations where what respondents say is studied with an attempt to disrupt their lives as little as possible. The behaviours, thoughts and opinions expressed are examined in light of existing theoretical perspectives to highlight social meanings (Henn et al. 2006). Flexibility is important during data collection as new ideas, issues and concepts may become pertinent. A key difference to quantitative research is that theories are constructed rather than tested throughout the research process. Qualitative research largely tends to be iterative, whereby data collection and analysis occur simultaneously; inductive, where broader more abstract concepts are derived from localised data and

researcher centred, where the influence and identity of the researcher is counted as significant (Denscombe, 2010). In my research, I transcribed and analysed as I interviewed, continuously referring back to the literature. My identity as a DSW was relevant in gaining access and in the interview interactions. This will be detailed later. I selected a qualitative approach as it embraces the idea of multiple realities. Such realities are shaped by their individual experiences and interpretations of the social world.

Interviews are an interactive process. Kvale (1996) points out that there are two philosophical orientations, which a researcher may take to interviewing. He refers to these as the miner and the traveller orientations. The miner orientation assumes that the informant is in possession of data or evidence, which if it can be extracted by the researcher will lead to answering the research question. As a traveller, the researcher acquires data or evidence, which may help to directly answer the research question but is equally likely to provide more context and a greater understanding of a wider range of matters of interest. This view, which represents an interpretivist orientation, is usually seen as providing a wide range of knowledge or understanding.

Positivists argue that knowledge has to be objectively sourced and that the researcher can be neutral but I believe reality to be constructed at least in part by the individuals own experiences and interpretations, influenced as they are by the historical cultural and social forces shaping available meanings. My own role as a researcher contributes to the generation of knowledge about the experiences and interpretations of DSWs and therefore I am influenced by constructivist ontology. The epistemological assumption of most qualitative approaches is that knowledge is value laden and subjectively constructed rather than existing 'out there' to be discovered in a value neutral approach. It is also an epistemological assumption in these approaches that what constitutes knowledge is also constructed through the interview process and that the interviewer brings their own experiences and value judgements (Knox and Burkard, 2009). When conducting a qualitative study, the researcher tries to get as close to the respondents as possible and they influence the research. To this end, I adopted the axiological assumption that I make my biases known as the researcher and position myself in the field rather than trying to eschew them because this is impossible (Creswell, 2013).

#### **4.4 Methodology**

Given the qualitative nature of my research design and the critical theory frameworks adopted, I originally intended to use a combination of participant observations and semi structured interviews with DSWs and with managers of disability support services. Through the interpretation of people's words and behaviour, the researcher is 'building theory out of the naked raw data that is available' (Thomas, 2011: 125). As the observer, I would have spent a considerable time period in the settings taking note of all that I had observed. Seeing what people do as well as hearing what they say are important variables in gaining insight to the nature of the work and the interactions that define it (Barker, 2006). It would have been vital to gain the trust of staff and service users and building up a rapport so the presence of a researcher would not be disconcerting. Observations would have opened up a deeper insight to the culture of the agency. However, access issues that arose in relation to protecting the privacy of service users meant that observations could not be included as part of the research process and will be discussed in more detail later.

Focus groups/ group interviews were considered as a number of people's perspectives can be obtained in one meeting and through the group discussion, interesting insights may have emerged. However, I decided not to use these because I was asking people about their understanding of the role and the tensions and constraints operating in their work and considered this would be best explored in a one-to-one conversation. Mason (2002) points out that there are practical and resource issues to be considered. This is a small scale study with time and budget constraints. The respondents generally worked shifts and this meant it would be difficult to arrange a suitable time in which to run focus groups. The semi structured interview was decided on as it allows respondents to talk in detail about the subject. This enables the respondent's point of view to be maximised and understood. Unlike structured interviews, in-depth interviews are open ended, using interview schedules where the intention is to capture the respondent's perspective for exploration (Bryman, 2012).



#### **4.4.1 Selection of sample**

‘A sample is a subsection of the population, chosen in such a way that their characteristics reflect those of the group from which they are chosen’ (Henn et al. 2006: 129). Because this is qualitative research, the richness of the information received was considered to be more pertinent than the number of respondents in the sample (Bryman, 2012). I considered DSWs with a minimum of one year’s experience in supported living settings to be the most suitable as they would be past their probation period and socialised into the setting. They were deemed to be able offer the most insight as they work in a frontline position with service users on a daily basis. I was interested in the processes of disability support work and the social, historical and cultural influences, which shaped such processes. Given that I selected DSWs as research participants, I have a basis for some generalisation about the social processes involved.

Theoretical sampling is where the phenomena of interest to the research are most likely to occur (May, 2011). Therefore, while generalisation may not be possible with populations, it is to the particular theoretical logic. Sampling must stop when theoretical saturation occurs i.e. no new concepts or insights central to the research are emerging. Given that I was interested in DSWs’ interpretation of their role, purposive and theoretical sampling were used. Frontline staff were purposively selected as my sample frame. Additionally, I was interested in the understanding of managers because they were likely to embody the philosophy of the organisation and I wanted to examine how formal values of the organisations were translated in the practice of frontline workers and the extent of connect and disconnect between both. Line managers are positioned between both. Convenience sampling occurs where easily available people are selected. For pragmatic reasons, I considered studying my colleagues but I chose not to as it would be difficult to maintain boundaries during the fieldwork. Further, my work base is in another jurisdiction and so is governed by different policy and legislative contexts.

My qualification as a social care worker and my experience of working in the field, including practice placements means that I am familiar with organisations that provide supported living services to adults with disabilities. There were several factors that influenced my choice of agencies. I decided to focus on non-governmental organisations with a mix of traditional longstanding and newly developed agencies in the west of Ireland. Not-for-profit or voluntary sector organisations are the main provider of

services in this sector and are well established in the West of Ireland. Snowballing was used where a network of respondents is built up through initial informants. This was achieved by e-mailing and phoning disability support organisations and gaining further contacts through them. Nineteen not for profit disability organisations were contacted to invite them to participate in the research. The initial intention was to carry out observations followed up by semi-structured interviews. Two of the agencies I contacted required the research proposal to be presented before their ethics committees who expressed their concerns regarding observations. Given the constraints emerging around access to workplaces for observation, I decided to focus my research on staff members employed as DSWs. My research proposal was submitted to the Research Ethics Committee of IT Sligo and approved. The amended participant information sheets (Appendices C and D) were forwarded to them. I work in the field and for some respondents these perceived connections influenced their decision to participate. They were informed that their involvement will contribute to increasing knowledge in the area.

#### **4.4.2 Research participants**

Of the 19 not-for-profit agencies contacted, 6 agreed to participate and 26 workers were interviewed. 27 participants were originally envisaged but one person failed to show for the scheduled interview. Their right to withdraw was respected. All respondents were employed in care/support roles in organisations in the west of Ireland providing services to adults with disabilities. Of the DSWs, there were 2 males and 24 females: 14 were employed full time and 12 were part time. Their experience ranged from the preset criteria of one year to over 20 years. Four had secondary level education; ten had a FETAC level 5 or 6 qualification; ten had a bachelor's degree and two had a postgraduate qualification. Eight managers were interviewed. Each worked directly as line managers of the staff interviewed. Three were male and five were female. One of the eight managers had worked as a DSW previously. Three managers were required to work a number of hours each week in the same role as DSWs. Educational backgrounds ranged between social work and nursing while one manager has a postgraduate qualification.

The organisations represented a wide geographic spread across the province. All are voluntary and funded from statutory sources. They each have a clear mission and ethos of person-centeredness, promoting independence and social inclusion for adults with

disabilities. Three are community based services for adults with disabilities who are allocated hours of support each week. Each of these services has a main central office space but DSWs are not based here. They work supporting service users in their own homes in the community. In one of these services, the service users have mild intellectual disabilities. The staff in this service are particularly focussed on supporting their community participation and helping them resolve housing related concerns. In the other two, service users' level of dependency ranged from moderate to profound. Staff in these settings provide support with personal care and tasks around the home and also support their social involvement.

The remaining three of the six organisations provide housing and 24 hour support for adults with moderate to profound disabilities with between 3 and 7 people living together in one house. Staff are involved in the day to day lives of service users providing personal care, teaching skills and encouraging community participation. Staff work different types of shifts including: split shifts where staff provide support at particular times in the day, such as the morning; 'long days' usually 12 or 13 hours in length; sleepovers, where staff sleep at the house but are on call during those hours and waking nights, where the service users have higher needs and require staff to perform regular checks on them.

	<i>Type of residence</i>	<i>Impairment</i>	<i>Level of staff support</i>
<b>Org. 1</b>	Own home	Moderate-severe	Allocated hours
<b>Org. 2</b>	Own home	Moderate-severe	Allocated hours
<b>Org. 3</b>	Own home	Mild	Allocated hours
<b>Org. 4</b>	Group home	Moderate-severe	Shifts
<b>Org. 5</b>	Group home	Moderate-severe	Shifts
<b>Org. 6</b>	Group home	Moderate-severe	Shifts
<b><i>Table 1: Profile of participating organisations</i></b>			

<b>Gender</b>	<i>Male</i>		<i>Female</i>	
	2		24	
<b>Full/part time</b>	<i>Full time</i>		<i>Part time</i>	
	14		12	
<b>Qualification</b>	<i>Second level</i>	<i>FETAC level 5/6</i>	<i>Degree</i>	<i>Postgraduate</i>
	4	10	10	2
<b>Table 2: Profile of participating staff</b>				

#### **4.5 Research Site**

Interviews took place over a three week period between the dates of June 18 and July 9 2014. I prearranged blocks of time (2-5 days) in each location and respondents selected a time and day within this, which suited them. They mainly met me in between their split shifts. Interviews were undertaken at respondents' workplaces, with the manager's consent. Four of the agencies provided a main office to use when conducting interviews. With the other two agencies, I met with respondents in the group homes where they worked. I met with them in the communal area when none of the people living there were present. I did not enter any private spaces. This appeared to influence how the interviews went compared to those carried out in a neutral space. For example, some of the interviews were carried out in the living room of service users who have chairs purpose-made to suit their physical needs. One respondent used these chairs as a frame of reference to talk about each service user.

##### **4.5.1 Designing and carrying out interviews**

The topic guides (Appendices A and B) were designed based on findings in the literature. Themes in the staff topic guide included: description of the work; perception of historical and social change; empowerment; positive aspects; challenges and how

they are supported; physical and emotional labour. The topic guide for the manager interviews included: description of the agency and their role as manager; understanding of the job for staff; support, training and supervision of staff; challenges as a manager and support and training they receive.

The questions were all open ended to encourage discussion (Hannabuss, 1996). The first questions were designed to develop a broader overview of their roles and responsibilities. Before commencing the interviews I carried out a pilot interview with a work colleague to test the questions and some adaptations were made. The topic guide enabled me to address all relevant areas of interest to me as well as allowing the discussion to move fluidly in the direction of issues raised by the interviewee. While prompts and probes were used, the data collected was largely guided by the interviewee. By allowing the interviewee to discuss topics using their own frames of reference, language and concepts, new areas could be explored from their point of view (Denscombe, 2010).

As the interviewer I needed to be able exercise good judgement about when to listen, intervene or prompt without interfering with the flow of the interview. In-depth interviewing may be criticised for lacking in scientific rigour as the closeness between interviewer and interviewee and informal 'conversational style' provides too many opportunities to influence the response through body language, questioning style or revealing their own views on the matter (Corbin and Strauss, 2008). However, to increase scientific rigour, all interviews were taped and transcribed. A key feature of the in-depth interview is for the researcher to develop a rapport with respondents. This enables them to feel comfortable and speak more freely. The advantage of using recordings is that it freed me to reflect on and engage in the interview without the distraction of taking notes. It also allows for validity as recordings can be inspected by others.

Each interview was scheduled for 30 minutes to an hour. Interview times ranged between 20 and 56 minutes. At the beginning of each interview, I thanked the respondents, explained the process and informed them of their right to withdraw at any time. They signed the consent form (Appendix E) and when they were ready, I began recording. Each interview was recorded using the 'smart voice recorder' app on my mobile phone, which can only be accessed with a password. After the interview,

respondents completed a short exit questionnaire (Appendix F) to collect demographic data such as age and qualification. The recording was immediately uploaded to 'drop-box' a secure, online storage system. Staff and managers expressed their interest in reading my finished thesis so I agreed to send a copy to each agency on completion.

#### **4.6 Data analysis**

The interviews were transcribed as quickly as possible afterwards. Qualitative data is about bringing meaning to a situation. Qualitative analysis works up from the data uncovering themes then exploring their implications (Creswell, 2013). I selected thematic analysis, which is a search for themes that emerge as important for describing the phenomenon being studied (Fereday and Muir-Cochrane, 2006). All transcripts were coded by hand. A theme is a category identified by the analyst in the data that relates to the research focus and provides a basis for a theoretical understanding of the data (Bryman, 2012). This form of analysis allows the researcher to develop a sense of order within the data while uncovering key themes that are pertinent to the research. Staff and manager transcripts were coded separately. Codes were initially made based on repetitions, commonalities, differences and connections to theory. Issues were grouped together and eventually key themes emerged. Bryman (2012) warned that themes should not be based on repetition alone but also their connection to existing theory and relationship to the initial research focus. Thus the process included continually referring back to the literature review and the research questions. Interpretations were ascribed later.

Through analysis of the data, ten overall themes emerged. Six of these arose from interviews with staff: Experience of social change; Labour process; Person centred approach; Relationship; Emotional labour and the Body. The remaining four arose from interviews with managers: Understanding of the job for staff; Support; Resource management; Labour process/bureaucracy. Within these themes, I identified five recurring themes, which were more prominent and appeared more regularly in response to a range of questions. They are: Professional relationships; Time; Professional identity; Policy priorities and Managerialism. These five themes draw on material from a number of the themes in the findings and this is illustrated in Table 3.

<b>Themes from findings</b>	<b>Themes for discussion</b>
<i>Themes from staff interviews</i>	Professional Relationships
Experience of social change	- Person centred approach
Labour process	- Relationship
Person centred approach	- Emotional labour
Relationship	Time
Emotional labour	- Experience of social change
The body	- Labour process
	- Relationship
	- Resource management
	Professional identity
	- Experience of social change
	- Emotional labour
	- The body
	- Understanding of the job for staff
	- Support
<i>Themes from manager interviews</i>	Policy priorities
Understanding of the job for staff	- Experience of social change
Support	- Person centred approach
Resource management	- Relationship
Labour process/bureaucracy	- Resource management
	Managerialism
	- Labour process
	- Resource management
	- Labour process/bureaucracy
<b><i>Table 3: Illustration of discussion themes synthesised from findings themes</i></b>	

#### **4.7 Ethical considerations**

Responsible research means taking the necessary steps to avoid breaching ethical conventions. The rights of respondents must be protected. Future researchers must be respected so that they will be able to carry out research in settings where relationships are preserved and undamaged. It is considered unethical for a researcher to misrepresent their identity to gain access to a setting and to misrepresent or hide information about the research being carried out when seeking consent (Erikson, 1967). Therefore, it was important to be open and transparent about the purpose of the research and how the data would be collected. To comply with standards set out by the Sociological Association of Ireland, informed consent was sought from all respondents in the research. Informed consent does not just mean signing a consent form but rather should be perceived as the outcome of a full understanding and willingness to engage in the collaborative process. There is a responsibility on the respondent to read the consent form and ask any questions before signing. Prior to engaging in the research, respondents were fully informed of the purpose of the study and its implications, how and why they were selected, their role in the study, assurance of anonymity and data storage and security.

The procedure of the study, the setting and how long it was expected to take was explained before beginning. They were given time to read and understand the participation information sheet and any questions were answered before signing the consent form. They were assured that their participation was voluntary and they were free to refuse to answer any particular question throughout the interview or to withdraw at any time without consequence. Henn et al. (2006) suggest that issues of subtle coercion could occur due to a power situation between researcher and researched. Thus, it was important to avoid showing any disappointment or disapproval throughout the interview.

The risk of physical or psychological harm to respondents is minimal in this research as they were not exposed to anything stressful, embarrassing or anxiety provoking. No deception was involved. Respondents were aware of their freedom to withdraw. Even though people may not be harmed, they may feel wronged by the research (Cassells, 1982). They might have felt threatened if their practice appeared to be under scrutiny. This is particularly pertinent at a time when the Health Information and Quality Authority (HIQA) are carrying out inspections of residential settings for people with intellectual disability. If a worker disclosed during interviews that they were particularly stressed or anxious, it would have been useful to direct them to a counsellor or provide them with helpline numbers as I am not a trained counsellor. There was a risk that during the interviews poor practice or even abuse would have been disclosed. It would have been necessary under a duty of care to report this. This was explained to each respondent before commencing the interview.

Anonymity was protected by using pseudonyms. The respondents were asked to respect the confidentiality of their service users and colleagues throughout the interviews. During transcription, pseudonyms were used for any names mentioned during interviews while the names and locations of the organisations were omitted. Due to the close proximity between researcher and respondents in qualitative research, full anonymity cannot be guaranteed (Patton, 1990). Thus a high level of confidentiality was assured. This means that an effort was made to protect their identity and information. All information regarding respondents, including recordings and transcripts was stored securely to be destroyed within the agreed timeframe of IT Sligo research protocols.



Pseudonyms were used instead of real names. The full names of respondents is on their consent forms but these were kept locked securely away at all times.

#### **4.8 Validity, reliability and credibility**

Validation of qualitative research largely stems from the positivist paradigm (Begley, 1996). Morse (1999) argues that qualitative research must not reject the concepts of reliability, validity and generalisation if it is to maintain its position as a scientific process. Scientific rigour demonstrates the integrity, competence and legitimacy of the research process. 'Validity concerns the extent to which observations and/or in-depth interviews achieve a close approximation to the 'truth' of a particular matter' (Henn et al. 2006: 176). This study seeks to get to the heart of how DSWs interpret and construct their role. Their unique insights would have been difficult to attain through quantitative methods. Denscombe (2010) points out that qualitative research cannot be replicated like an experiment as there are many variables, which impact on that particular piece of research, including but not limited to the involvement of the researcher in the collection and analysis of data.

External validity is the extent to which conclusions of the study generalise beyond immediate subjects and circumstances of the investigation. The results from qualitative research are usually detailed but come from a small number of respondents and thus cannot be generalized (Converse, 2012). However, I may be able to draw some parallels between the findings in the literature and my own primary research. Silverman (2004) promotes the systematisation of the research process with all field notes and procedures documented for inspection by other researchers. Some researchers argue that generalisability is not necessarily the aim. Patterns and behaviours of a specific group can be described in detail rather than endeavouring to ascertain general rules of human behaviour (Ward-Schofield, 1993). However, by exploring a range of qualitative research studies on a particular area, it may be possible to determine generalisable trends.

Confidence in a particular piece of qualitative research can be enhanced using triangulation (Denscombe, 2010). For this reason, two data sources were used in the fieldwork, i.e. disability support staff and their managers. Denzin (1970) identified four types of triangulation, two of which are pertinent to my study. Firstly, theoretical

triangulation where more than one theoretical position is used to interpret data; I use critical theory to enable me to interpret the data drawing on feminist and disability perspectives. Secondly, data triangulation where several sampling strategies are used to gather data so that segments of data on a variety of people within different times and social situations are gathered. I interviewed 26 DSWs from six separate agencies using different approaches to supported living for people with disabilities. In addition, I interviewed 7 managers whose insights were a valuable contribution to understanding the contextual influences on the DSW. Methodological triangulation occurs where more than one method is used. While I sought to combine interviews with observations access barriers prevented this.

#### **4.8.1 My position in the research**

Decisions about the research site, respondents and the research question are all influenced by the researcher's preconceived knowledge and expectations. I work as a DSW and it was this position that inspired me to pursue this course of research, influenced how I gained access and impacted on how I approached the questions. As an insider, there was a danger that I would develop too empathetic a view of the group studied through close identification with them. However, some feminist researchers contend that identity, values and beliefs of the researcher actually facilitates the research and rather than disregarding this it should be exploited to enable entry to areas that may be inaccessible to other researchers with a different self (Denscombe, 2010). Letherby (2003) suggests that there has been a shift in thinking whereby involvement has come to replace objectivity in research. I designed my topic guide in light of theoretical perspectives in the literature while also reflecting on my own position as a DSW. It was designed in consultation with my supervisor and piloted with a colleague in the sector. I interviewed managers to allow for their perspective to emerge in the research and to avoid the bias that may have been a consequence of having only researched one group.

Despite taking these measures, my position as insider influenced interactions. During analysis, I realised there were occasions during the interviews where because I already knew (or at least thought I knew) what respondents were talking about, I did not ask further questions. For example, I did not ask for clarification on certain names of medications or acronyms that may be considered 'common knowledge' among staff. Feminist researchers would argue that the researcher has an important role in the process

and they should actually take responsibility for what they write rather than feigning detachment (Letherby, 2003). Some would further argue that the identity, values and beliefs of the researcher should be used to get access to areas that less connected researchers would get at (Denscombe, 2010). However, Duncombe and Jessop (2005) warn against 'faking rapport' as unethical research practice. In my view it would have been unethical to hide my position as a DSW from respondents because this is a material influence on how they viewed me and how we interacted in the interviewing context. While it may have enabled respondents to speak more freely, the act of not telling them that I was also a DSW may have been interpreted as hiding relevant information about myself. In my research I gave full acknowledgement to my position as insider and the impact that had but also took measures as outlined above to guard against bias.

#### **4.9 Emerging issues**

Access is difficult when researching 'vulnerable' groups that is groups of people who have less power in general terms and also in the research relationship and may be more susceptible to exploitation by the researcher. While power differentials exist in many research relationships, when the individual or group is also less powerful in the society, such differentials are exacerbated and need specific attention. Gatekeepers were sought out by e-mailing the managers and directors of various disability support settings to seek permission to carry out fieldwork within their organisation. It was necessary to seek ethical clearance individually with each organisation. Concerns arose particularly in relation to the proposed observations. Although it was intended to observe staff only in their work environment, vulnerable adults would also have been present. Most organisations immediately refused access for observations due to concerns about confidentiality and protecting the privacy of service users. However, they allowed interviews to take place with staff members. Thus, it was necessary to compromise on the methodological approach in order to gain permission. The interviews took place in quick succession over a period of three weeks. Three weeks of interviewing was sufficient on a practical level to accommodate people but spacing out interviews would have allowed for more time to reflect on emerging themes. I transcribed the interviews after each one was completed. The process did highlight specific concerns emerging, which I took to the next interview. However, greater spacing of the interviews would in retrospect allow me to reflect on emerging concerns to a greater degree than was

possible in the time frame. Access issues may create a larger issue for service users as their voices are continuously filtered out (Tuite & McLean, 2015). This means that policies and services are not informed by the voices of the service user.

#### **4.9.1 Limitations**

While the research design sought to address epistemological and methodological issues, it is not without its limitations. Reactivity can occur where respondents consciously or unconsciously alter what they say during fieldwork. The data would have been invalidated if instead of real world relations, what respondents want you to hear was recorded. They may have tried to present themselves in a particular manner to create a favourable impression (Goffman, 1959) and this was difficult to identify. Aronson (2008: 152) notes that our biographical memory tends to distort over time. They may have simply forgotten details or remembered a story slightly differently to how it actually happened. Additionally, they may have been afraid to criticise their employers, employment conditions or colleagues (Windley and Chapman, 2010). It is not possible to fully control for these issues. However, to alleviate respondents' fears a rapport was built with them so the presence of a researcher was not perceived as a threat. This was partly achieved by informing them that I also work in the field and created a sense of shared understanding. Their experience and insights about the role of the DSW are central to the research focus and their interest in participating and my commitment to hearing what they had to say was an important basis for a more equal relationship within the research experience. In the choice of research site, my decision to focus on non-government organisations in the not for profit sector means the experience of those working in the statutory and private for-profit sector are not addressed.

## **Conclusion**

To conclude, this chapter presented the considerations that informed my research design so as to enable me to examine the experience of DSWs and the influences on their work identity. The next chapter will present the findings from the interviews using extracts from the interview data. The themes identified serve to convey their perception of the role and raises questions regarding the challenges of the work and the support needs of disability support workers.

## Chapter 5: Findings

### Introduction

This chapter presents the findings from the interviews with staff and managers, organised into the key themes. The first section delineates the staff findings. Six key themes emerged through analysis of the staff interview transcripts: Experience of social change; Labour processes; Person centred approach; Relationship; Emotional Labour and The Body. Respondents were consistent in describing experiences that reflect a working environment, which is multifaceted, ambiguous, physically challenging and emotionally strained. The second section outlines the key findings from interviews with managers. Four key themes were apparent: Understanding of the job for staff; Support; Resource management and Labour process/ Bureaucracy.

### 5.1 Interviews with staff: findings

#### 5.1.1 Experience of social change

Respondents were asked if it was better now for people with disabilities than 20 years ago to explore their perception of change on a historical and social level. Five respondents commented that they did not feel they could answer that as they were not working in the field 20 years ago. Those who were in the field for longer were able to relate it to their own experience, which for the most part was positive. They told about how the standards of housing and quality of life for service users had improved, better equipment, more public acceptance and more organisations that support people with disabilities. They explained how service users were increasingly involved in the community and being supported to build greater family connections.

Well the times are changing the whole people in care thing is changing. Especially with HIQA there's a lot more emphasis on care plans, goals. There wouldn't have been that much of an emphasis on it when I started 12 years ago... like when I started here, two of the service users shared a room for years and years but they shouldn't have shared a room but that's gone now (Kelly) [1278].

I used to work in a psychiatric hospital and a lot of people with disabilities were in those hospitals... They were just there and people never knew if they were able or capable. At that time that's the way it was but it has changed for the better (Erin) [3020].

These compliment evidence in the literature documenting the transition from the medical to the social model, policy changes in relation to deinstitutionalisation, the emphasis on normalisation, the concepts of rights rather than charity. Respondents also shared negative experiences and some of these were related to the attitudes of the general public towards disability. The increase in regulations means they feel more restricted and have reduced autonomy in their work approach. Some also suggest that despite all the changes, practices from the past have remained. It may be that the form has changed but the end result is the same i.e. people do not get what they need or bureaucracy works in a similar way to how institutionalisation worked.

Things have gotten a bit more... eh... in that everything has to be by the book. Do you know what I mean?... If it's not in their care plan you can't do it, so if a lady asked me to hang out her clothes on the line, I actually can't do it so I think that's just really crap. You know? Like, 'because they say if it's not in their care plan and you trip going out to the line, you're not covered by their insurance, so I think that's wrong... You can't really do anything by your own initiative (Sinead) [295].

They live in a lovely house in the community but it still feels mini institutional to me. It's very homely but still because we have this nearly clock in our heads, staff coming in and staff coming out it still feels like a work environment in lots of ways (Aoife) [2893].

### **5.1.2 Labour process**

The staff interviewed described the tasks that they are required to carry out in their role. This includes personal care, supporting community participation, housework and administrative tasks.

You go in at eight and read the report... then around ten past, quarter past eight we start getting them all up for showers and that, change them and do the beds and they have their breakfast and then after the breakfast they go up to the day program. They stay there 'til four o'clock... and then they go back down at four o'clock. A lot of them are in chairs all day so usually we lie them down on the bed between four and half four for half an hour and then they get up and they're getting ready for their tea. They get their tea then around half five... and then at seven o'clock they get their medication and something light like a yoghurt or a piece of custard before they go and they have their drinks. Then you go down brush their teeth get them ready put them into bed so they're all in bed then, before the night staff come in (Collette) [1845].

Respondents also frequently referred to the context within which they carry out these tasks: a context marked by constraints of time, money and the opportunities offered by

new equipment. They generally had a positive view of the equipment as they felt it made it easier to carry out the personal care tasks in particular.

Well the hoist takes the major work out of it so you let the machinery do the hard work and you assist the hoist (Amy) [485].

The ratio of staff to service users was raised as a concern by some respondents. In some instances this is 1:6. Their perception of time and general funding was more negative as they felt there was not enough to complete their job effectively.

Sometimes you feel there's not enough hours in the day. You're rushing and if you're out you're trying to get back. You're put on a time limit 'cause the staff are going off... You're trying to get a lot done in a short space of time. It's hard work. We try not to get stressed. It is a stressful job (Fiona) [781].

Their perception of their connection with their managers also appeared to have an impact. For the most part they praised their direct line managers but felt disconnected from any managers 'higher up'. Most did not believe they would be consulted by these managers.

...when area managers would come in and they'd nearly find the one thing you hadn't done or over looked and I would get very stressed out by the fact and very p\*\*\*ed off to be honest. It was kind of like ye can only see the one bad thing and no praise for all the positives that have been done (Emer) [2354].

### **5.1.3 Person centred approach**

The key issue under this theme was empowerment, supporting service users to be more independent in their daily lives. Three clear elements emerged in relation to this and were largely dependent on the level of disability for each service user and the approach the worker adopted to address this. The first instance is where service users are largely capable and respondents describe how they teach a new skill and gradually fade out of the process until the service user is carrying out this new task independently. The tasks described are all based around the home including food preparation and housework.

Say now one of the girls here. She's blind in one eye and she has tunnel vision in the other and she loves tea but there's so many health and safety issues, because of her sight, around using the kettle so we wanted to support her independence around making the cup of tea herself... so we got someone from the national council for the blind to come here and give us advice on what to do so she advised getting a kettle of a very bright colour, putting it on the tiles that were you know no pattern so that she could easily identify that was her kettle. She showed us a step by step



way for her to be able safely make a cup of tea like getting a cup, filling it up with water not to the top, then just using that cup to put into the kettle that she's never going to overspill it. She'll never put in too much water, there's only going to be enough for the cup and we did this over and over and over again with her, trying with a staff there and now she's able do it herself (Emer) [2328].

The second instance is where service users have quite a severe disability and are usually older so staff are focussed on maintaining the skills they already have but do the things for them that they are not able to do.

We have one lady who'll put her hand out for shampoo and she can wash her hair with one hand and she'll cover her eyes with the other. Another lady will dry under her arms to a certain amount and you'd help her and another lady she just won't engage with you but when it comes to drying her hair she'll hold the hair dryer (Aoife) [2881].

The third instance is where service users have a profound disability and supporting their independence is on what may be considered very small levels, such as having a person hold their own cup. Seemingly small things such as pushing an arm through a sleeve are encouraged and also telling them what is happening and offering different choices are methods used by staff.

The guys that are less able... eh... this isn't really encouraging independent skills but it's showing them. I might bring one of them out while I'm emptying the dishwasher and they'll see me doing that. They'll see me putting the bowls up. It's just keeping their minds active (Stacy) [1198].

Some respondents expressed that if they did not encourage independence for service users, they would become more dependent on staff and shared the challenges they faced around this.

It's nicer to see them doing things for themselves... because if they don't they'll lose them skills and be expecting you to do things. (Rachel) [1592].

It's really giving the responsibility back to people and say look if you want this to happen in your life then you have to put in the effort and you have to make it happen for yourself and we can do as much as we can to support you but we can't make it happen. One major thing I'm finding is that two or three of the service users are obese and they'd all tell me they want to lose weight but realistically they want me to lose the weight for them... and it's a big job to make people understand that all that power is in their hands (Claire) [617].

Respondents also expressed the difficulties they faced when they desired to encourage independence but the amount of time allocated to them meant they had to make compromises.

*Kate:* Sometimes I think the hours we're allocated are the most stressful. Sometimes I think it's better to do things gradually... but sometimes they'd linger 5 minutes or 10 minutes over breakfast or even with the hygiene side of it they could spend longer in the toilet or washing or something and you're very conscious that they have have all their exercises to do yet so it can be frustrating when things is rushed.

*Interviewer:* How do you manage that?

*Kate:* Well you just go in and you try and get everything done in the time that you've got. Even before they'd get up you'd have the kettle boiling and even you'd ask them before they get up what they want for breakfast so you can have it ready for them. There's many a time they're capable of getting it for themselves but so that they can have more time... you just kind of do these things (Kate) [94].

Respondents frequently spoke of their role in supporting service users to carry out everyday activities in the community. They all described the opportunities for social inclusion in a positive light.

Their whole way of life has changed because they're so involved in the community. They can now use the local beauticians and chiropodist and hairdresser and barber and they go swimming in the local pool. Before in the centre it was all centre based so the hairdresser would come in and the chiropodist would come in but now they get to know the people going so it's fantastic like that (Megan) [2690].

Negative experiences were generally to do with public attitudes but a key issue was when service users refused to participate in the community. They recognised that noise, crowds or preferring a familiar routine are all reasons for this but frustrations were felt nonetheless. Inclusion is contested or nuanced as experienced by the workers and the people with disabilities themselves as evident in what this two respondents had to say:

I do think all this stuff that has come up about preventative of abuse is really good. I kind of find it hard that say if you're out in the community and somebody might have challenging behaviour and they may sit down and start screaming and kicking. You're like 'come on let's get up. Let's get up' and the person out in the public is thinking you're abusing them because people don't have an awareness of say autism... so people think everything is abuse now (Amanda) [2561].

People with disabilities aren't as social because they have their routine and they're probably used to the way that is and they can't differ from it... Say people don't always want to be put into a situation they haven't always been in. They're not as spontaneous to do things because they're so used to things the way they are... You can't make them do it. I don't know (Sarah) [49].

#### **5.1.4 Relationship**

When asked about positive experiences of their work, respondents frequently responded with regard to the relationship they have with service users and how they engaged with one another. They talked about the personal rewards they gain from helping others and the simple element of having a chat or laugh with service users.

They do have the one-to-one with the staff when they are feeding them. I love that part of the day. You start talking to them and getting reactions. You do notice things. You'd have a little chat with them and ask them what they did at work... I know there's one fella that if he's been acting the maggot down there he'll start roaring laughing when he comes back up and you say what were you doing down there? Why were you falling off your chair? And he'll start roaring laughing (Ciara) [1113].

I like when you go in and have a chat, the reaction you can get from somebody once they see you (Collette) [1841].

Issues of trust and building up a relationship over time emerged in this theme. Respondents also appeared to see a connection between building up a relationship and being able to support independence.

I guess it would definitely be over time. What I would do with people is build up a relationship first because a lot of the people, they're very cautious. They've a lot of hurt from their pasts, not them all but there's some that would be very wary of new people but when they come into our service it takes a long time to build up trust (Ruth) [740].

I like that I'm working with the same people all the time so you can build up a relationship with them... There's one person. Now he has passed away but from working with him he had different cries and I could tell if he was in pain or if he just wanted to be moved in the bed because he couldn't move himself... you wouldn't know straight away but after a while you'd get to know them... I've been here 15 years and worked with the same people all that time (Collette) [1837].

When respondents were asked what qualities and skills were required to work in this sector their responses were generally relational. Characteristics, such as patience,

empathy, understanding and passion were frequently listed. Few mentioned qualifications but instead placed emphasis on human qualities and some suggested these to be innate. They talk about having common sense and treating service users the same as you would friends and family.

I think you're either that type of person or you're not. I don't think you can learn it... [You need to be] very understanding, empathy understanding and patience, patience, patience. Lots of patience (Alison) [854].

You actually have to be like a mum too. You have to be able cook dinners, make the house homely, all those things (Amanda) [2569].

### **5.1.5 Emotional labour**

When asked about the qualities required to work in this field, some respondents suggested that a good sense of humour was necessary to be able maintain a cheery atmosphere for service users. They also talk about how they should just 'get on with it' in showing emotions they don't actually feel to elicit a different emotion in service users.

I think you need to have a good sense of humour because you go into the person and you don't know what sort of mood they're in so you have to go in and lift their spirits, make them feel good about themselves and you have to be strong as well (Julie) [941].

You hear the intimate details of most people's lives and some of it can be very harrowing stuff. These people are very damaged a lot of the time and not just because of their disability, they're damaged from childhood... so I think to be easygoing and that you're not easily shocked... it can be very, very challenging and sometimes you do get burnt out supporting certain people because it can be very, very draining (Ruth) [728].

Because of the level of challenging behaviour it was very difficult to keep being upbeat and keep trying new things and keep going to someone and come up with new agreements when they're basically kicking the crap out of you every day (Emer) [2345].

Many respondents shared about the unpredictability of the work, having to respond rapidly to extremely dangerous and stressful or challenging incidents.

There's one lady I worked with... and it was as if all of a sudden one day she just went mad. We were actually frightened ourselves. She came in and she had a knife. This was on the Saturday and she was going to kill us and she was going to kill herself. Everything! She just really snapped. And there was a lot of help in the

house. The ambulance came and brought her and, you know we had to get counselling afterwards because geez we were so afraid and she had the knife in the one good hand she had and she was... ooh! It was frightening! (Kate) [90].

We had an awful incident in the house three years ago where a lady went through a severe schizophrenic stage and depression stage and tried to, she banged her head severely off the wall and someone had to sit beside her 24/7 so you were sitting beside her 24/7 to stop her from banging her head off the wall but while you were sitting with her she was trying to punch you, bite you and she'd cry constantly so listening to this whimpering and crying all day long and on edge...I always would have said I'd cope really well in these situations and it was fine but I was working three long days in a row and the particular lady would usually be better for me cause I had known her so long and she made me cry out of pure frustration (Megan) [2771].

Many respondents discuss the tensions they face because they are paid support workers and are expected to maintain boundaries. They talked about how they get attached to service users and the emotional difficulties they experienced when service users were sick or after a service user has died.

Just last week one of the service users passed away and it's hard to draw the line where it isn't your grief because they're not your family but you have worked with this person for years. It is hard to see them pass away (Collette) [1913].

Almost all respondents were able to say they had no difficulties separating work life from home life.

When I'm off I'm off. I don't think about work. When I'm at home, I just switch off. I don't think about work and when I'm at work, I just think about what I've to do in work (Sean) [132].

When asked how they are supported, most spoke favourably about their managers and colleagues.

I mean the staff themselves are always a good support and if we've had a tough day we'll take 10 minutes out and go get a cup of tea because we know that going home stressed is no good either (Debbie) [1492].

There's a counsellor available or you could always talk to your team leader or there's your line manager and you can talk to the counsellor and it's completely confidential. There is somebody to go to if you need it (Linda) [1781].

Some also had a negative perception of debriefs as they saw them as criticisms of their practice.

The unit director has done a debriefing a few times but sometimes they work or they don't work. Sometimes the debriefing can make you feel like you've made a mistake (Ciara) [1073].

### **5.1.6 The body**

When talking about caring for the bodies of service users, respondents comment that because they are getting older, their needs are increasing and the work is getting more difficult. The bodily strain they experience is related to personal care as well as challenging behaviour.

I could come in in the morning and by 10 o'clock have every kind of bodily fluid you can imagine on me and by lunch time be sent home sick because I've been bitten by a service user or attacked. Or I could have my clothes torn, ripped if one of the service users is in a bad mood (James) [2247].

I know sometimes on the buses sometimes, just lift them in rather than bring the hoist down, you know which is so wrong but sometimes we're rushing to get somewhere and you just have no choice (Edel) [2492].

This is having an effect on staff member's bodies as many share that they are having problems with hurting their backs or other parts of their bodies.

Even though we have done all the training for back care and everything, I still have a sore back a lot... I take painkillers and if it gets very bad, I just get extra careful (Lisa) [231].

I've worn discs just wear and tear from the job. I just kind of get on with it... but then everybody's complaining about their back problems. Service users are getting older. Their needs are getting higher and everything is just getting heavier and harder... It's a lot of repetitive strains. You're doing the same movements all the time, sure even rolling service users in bed to change them and that so it is physical (Michelle) [2052].

Respondents discuss the physical and mental strain of the long shifts and the lack of breaks and the exhausting effect this has on them.

The 13 hour shifts, even though it flies by, 'because you're kept going, going, going... 'cause definitely if it's a day that the service user is in bad form and you're in for a thirteen hour shift sometimes even if you could just sit in your car for twenty minutes and just take a breather cause no you don't get that at all. You know that service user could be screaming all day and being so vocal and you don't get a chance even just to sit down by yourself for ten minutes (Edel) [2504].

Some commented that their diets are affected, partly due to poor self care but also due to limited time.

I smoke as well you see and I eat a lot of junk as you can see with the biscuits (Ciara) [1073].

## **5.2 Interviews with managers: findings**

### **5.2.1 Understanding of the job for staff**

There are different levels of understanding of the job for managers. One originally worked 'on the floor' and three have allocated hours to work with the service users so their knowledge is experiential. Because they work closely with staff and see what they do, their understanding of the job appears to be quite clear as the tasks they listed were very similar to the descriptions given by staff.

I was one myself so I can go on my own experience. They're there to support the person to be independent, not to do everything for them that they can do for themselves, d'you know what I mean? and to be able take direction. They need to have empathy, understanding and patience because it is quite a difficult job. It's a lovely job and we have great staff here. If you don't like it you won't just stay in if you're, you won't just put up with it. You need to have some sort of a passion for it... I empathise with them because it's a difficult job. I always say if you were out digging spuds it'd be easier sometimes. At least you can see what you've done. It might be a day and you mightn't see what you have done but for the person you're working with you could have done loads (Patricia) [60].

Providing individualised support and care in a holistic way, from intimate care and feeding them to taking them out on social activities and going on holidays with them so it's looking at the whole picture (Roisin) [41].

Challenges for staff as the managers saw it included maintaining boundaries, lone working, mental strain, safety during challenging behaviour incidents, level of disability, coping with change and accessibility in the community. These again were similar to what emerged in interviews with the staff. They recognised that they were responsible for exerting some of these challenges due to external pressures from their own managers and HIQA.

There's a lot of pressure with paperwork and it impedes on your time physically with the service user... Everything has to be recorded and documented. Because of the budget cuts the ground staff hours have been reduced in that they have to be uber efficient in what they do. We have six service users and three staff. In the morning everyone has to be up, washed, showered, assisted with dressing, assisted

with eating, medications given, logs written and all done by half ten when they go to their day service. That used to be about twelve o'clock so it was much more easygoing on the service users rather than just up out and go (Eugene) [60].

Managers were asked what they thought the needs of staff were and they listed such factors as learning, more hours, better pay, to feel valued as employees, recognition, support, be heard, have supervision, belonging, safety, fulfilment, satisfaction and understand their role.

[Staff need] to be heard, to have ongoing supervision, to be able to influence the direction of the service based on their experience working with individuals. A key need is also to feel a part of the service, that they're not working for me but we're all working in this service together, so a sense of belonging and also there... eh kind of has to be opportunities to enjoy things together outside of the work remit to build up a good bond and there's an element of trust (Paul) [122].

### **5.2.2 Support**

It was clear from interviews that managers have basic levels of support that they must provide to fulfil requirements set out in their organisation's policies and procedures. Basic requirements are set out with regard to training, supervision and debriefing after challenging incidents. According to the managers, staff receive plenty of training with regular updates. These are controlled by HR and as people are 'due' specific training, the manager is notified who must then accommodate for that staff member to attend. Basic training requirements are informed by HIQA standards. They include moving and handling, fire safety and first aid. Supervision and debriefs are standardised processes, which are documented.

Staff training takes place over the first two weeks of their induction combined with supervision and then for the first three months of someone's role here, they would receive supervision once every three weeks, and after three months then it goes to once a month and after six months it goes to once every six weeks (Paul) [48].

We have standard training organised through the agency. We get emails sent from the training coordinator saying you need to release this staff member for this particular training on this particular day and I would do my best to cater for this (Eugene) [124].

We have a debriefing process. In units with challenging behaviour, they have personal alarm systems so they can call in outside help to come in. After an incident they fill in an incident report. The team leader would offer debriefing and support and then they come to me (Roisin) [84].



Managers also spoke about how they provided support for staff beyond the basic requirements. This suggests that they have a good understanding of the job and challenges for staff. They shared about having an 'open door policy' so staff could come in at any time or allowing staff to phone them any time. These are informal meetings that are not recorded. This creates loyalty among staff.

If staff have an urgent need, a child sick at home or a personal difficulty, come to me and I will get someone else to step in for you. I'm flexible on that (Joe) [110].

One of our service users was admitted to hospital with cellulitis, caused by skin picking. It's quite serious in that we need to alert the GP and get her to A&E straight away... That happened here to a staff member and she would have rang me and asked for support and advice on the situation so that's where I come in to assist her and debrief her on it because she needed someone to talk to... so staff need to talk about it and that's what the individual support meetings are for. It's not just for when you pencil them in in the diary but having them when you need to have them (Miriam) [65].

Support afforded to managers appeared to be less standardised and at the discretion of their managers. Some spoke favourably about having good support but others got little to no support.

I receive support from my area manager who meets me on a regular basis for support meetings, we had one just this morning and she's always available on the other end of the phone if I need her help (Miriam) [101].

[I get supervision] from my manager but she doesn't get to see me working, whereas I get to work alongside the staff I'm supporting (Heather) [141].

I suppose, there's no formal training for me and who do I, who mentors me?... that is a weakness (Rita) [239].

### **5.2.3 Resource management**

Managers informed me that all the staff are employed by the agency. None of the organisations use agency staff. Some have a relief panel but they are interviewed and vetted by that organisation. Staffing is largely determined based on the needs of the service user. It is also controlled by EU directives for breaks and gaps between shifts. Managers typically explained the system for ensuring each hour was covered. They considered equality for staff with regards to weekends and nights.

Basically what I did is in the early stages I looked to the individuals who were availing of the service and what type of service they wanted and then put in place

the shifts to respond to the hours... the roster changes according to the lifestyle and the interests of those we serve (Paul) [103].

It's done on a computer system. I know the contracted hours and I know I have 24 hours a day, and the number of people needed per bungalow and I have to work within EU directives making sure people get breaks and a gap between shifts (Roisin) [64].

While managers may strive to ensure appropriate breaks for staff, this does not appear to happen in reality as Roisin's statement conflicts with Edel's (p.60) comment that she did not get any breaks on a 13 hour shift. One manager shared how he allowed staff to plan their own rotas and he supervised the process.

Each house has their own roster and I gave the staff the power to do their own roster. They do their own rostering within reason (Joe) [90].

The managers generally have a certain budget allocated, which they can use throughout the year. They must complete reports rationalising their spending. The biggest issue managers spoke about in relation to finances was the cutbacks made during the financial crisis and the impact this was having on the service.

Lack of resources, financial. It means I have lack of staffing as well. My biggest challenge at the minute is ensuring I have enough staff to manage these houses. there's very little funding coming from the HSE, which puts extra pressure on me.... I just apply to the HSE for funding and hope we get it but at the moment it seems to be not there to get it so it's a tough job to get funding for extra staffing (Joe) [63].

I suppose that whole social model is being eroded a bit at the moment through lack of resources. On one hand, it's being espoused very much about person centeredness, you know, the person being in charge, being in control of services. We're only following the client and services being there to support that but in reality with the budget cutbacks, that's not happening. It may be an aspiration but it's not actually happening on the ground as much as I'd like to see it and I think that's mainly resources, you know, with cutbacks and budgets but I suppose that's out of our control (Rita) [64].

Training is very difficult in the current financial situation that we're under so we try to do the best we can (Paul) [157].

The reality is, it's halfway through the year and still we haven't received our budget from the HSE going forward. Normally we have to send in the rotas to senior management and they try to squeeze the bejaysus out of us. Even a half hour every morning is a massive saving but we used to have a lot of time to get service users up but now it's a big rush (Eugene) [95].

#### **5.2.4 Labour process/ bureaucracy**

Managers shared the high level of administration that is required of them and the demands they face in keeping these up to date. Responsibilities, which originally would have belonged to HR or other managers higher up within the organization, have now been passed to them.

Keeping ahead... eh, keeping ahead of HR issues, keeping your files up to date, keeping memos... but then you have to back up and have all the evidence and the files and the folders and written documents and policies and that's getting more complex...em... and having things in date (Rita) [132].

Trying to keep on top of the management side, attending meetings, doing support contact with the team and all the increasing regulations that have come on board with HIQA, audits and all that. There isn't enough hours to meet that... We find that we're having to do extra office hours to meet that (Heather) [53].

I'm getting more responsibility such as sending different forms to HIQA so my role has changed...Any new software systems, staff clock in their hours and we manage the payroll. That would have been done in an office somewhere now we do it here (Eugene) [133].

In turn, managers are recognising that duties, which they would have carried out, have now been transferred to the staff.

There has been a lot of extra paperwork and procedures that they have to follow up of late and their contact time with service users is being reduced because of cutbacks. You might have had half an hour before service users come back from day centres or in the morning after they leave but that's been cut back (Heather) [58].

When managers were asked about challenges they faced, a key concern they raised was a perceived lack of fit within the overall system. They shared how they attempt to manage the concerns of staff and service users but are forced to wait for them to be addressed outside of their remit.

I managed [a staff situation] well from my perspective but it didn't get managed from the top down... It's dealt with now but it was drawn out and took too long and when it gets drawn out it gets exasperated (Patricia) [99].

Trying to achieve things that you can't, services outside the organisation and people being on waiting lists. It's hard to get things done...In the meeting I just had about a service user whose mum passed away... so we've looked at ways of dealing with her grief. As a manager you can't give an answer that you don't have. We've decided in that meeting she will need a counsellor or psychological input

but it's really hard to access psychology because of the long waiting lists. You always want to do more than you actually can (Miriam) [37].

## **Conclusion**

This chapter presented key themes that emerged in the interviews. Descriptions of physical and emotional labour emerged as salient with findings in the interviews. Further, the relational aspects appear to be hampered by austerity measures to reduce staffing and resources. The following chapter will address the 5 key themes which emerged from the findings presented in this chapter.

## **Chapter 6: Discussion**

### **Introduction**

In this chapter, key themes from the interviews will be discussed. Overall ten key themes emerged in the findings. They are: Experience of social change; Labour process; Person centred approach; Relationship; Emotional labour; The body; Understanding of the job for staff; Support; Resource management; Labour process/bureaucracy. From these a number of interesting discussion points arose. These were synthesised into five themes to be explored in greater depth: professional relationships; time; professional identity; policy priorities and managerialism. The discussion themes weave intricately through those in the findings, conveying their interlinking influence on the overall experience of the worker. This chapter will explore (i) professional relationships and their impact on the role of the DSW. (ii) The barriers and tensions central to the concept of time will be explored. (iii) It discusses the formulation of professional identity in relation to physical and emotional labour. (iv) Policy priorities and how these change and impact on the role of the DSW will be explored. (v) Finally, it will address the impact of neoliberal ideologies on the landscape of disability support, deconstructing the rise of managerialism in not for profit agencies.

### **6.1 Professional relationships**

Relationship emerged as a key theme in my findings. Staff perceptions of their relationships with the individuals they support is somewhat lacking in research in this sector (Iacono, 2010) so I decided to explore this theme in greater detail. There is a difference between personal and professional relationships. The main distinction is that staff are paid to work with service users while there is no financial element in personal relationships. Professional relationships usually differ from others in that they are temporary and are not as deep emotionally. The importance of the professional relationship was particularly stressed by Trevithick (2012) who observed that the quality of relationships that is formed between staff and service users is affected by existing knowledge, skills and values that they bring to the work. DSWs are unique in that they spend long periods of time with service users and the potential exists to build strong relationships. In order to be able to effectively work with service users, encourage them to be involved socially and empower them to be in charge of their own

lives, people must first be able to trust the people supporting them. This may take longer for people with disabilities as they have numerous professionals coming in and out of their lives. Respondents in the study expressed how knowing people well, having built up a relationship meant that they were able to recognise and respond to the needs of service users quickly and appropriately. The time it takes for this depth of relationship and understanding to emerge must happen at a pace set by the person themselves. Pace, however is constrained by external factors.

Every relationship is unique, making it difficult to define specific factors that encompass a relationship (Cheetham et al. 1992). Trevithick (2012) argues that it is essential to establish sound working relationships as they are central to empowerment and growth in a professional context. A good working relationship provides a solid foundation for future work. In an effective relationship, the DSW creates an atmosphere that eases the person's anxieties so they feel free to engage and also helps them to maintain their sense of dignity and worth through participation (Trevithick, 2012). The DSW provides a firm sense of security. This is called holding and has its roots in psychodynamic psychology (Thompson, 2009). This is essential as was highlighted by Ruth.

‘You hear the intimate details of most people’s lives and some of it can be very harrowing stuff.’ (Ruth)

Care organisations frequently warn against ‘over-involvement’ and promote the maintenance of a professional distance to uphold the formal image of a worker - client relationship (Aronson and Neysmith, 1996). The discourses of professionalism require people to be separate and maintain emotional distance from those they seek to support. However, this conflicts greatly with how respondents perceived relationships. They placed a high emphasis on their importance to effectively work together and personally viewed them as positive.

‘I like when you go in and have a chat, the reaction you can get from somebody once they see you.’ (Collette)

Relatively small responses from service users such as a smile or laugh may be fulfilling for the worker (Kittay, 1999). Personal rewards can be gained from the work such as fulfilling a ‘fundamental and natural desire to be and to remain related’ (Noddings 1984:53).

Building relationships involves a number of skills that require full use of the self (Trevithick, 2012). Respondents frequently listed personal characteristics as significant.

‘...very understanding, empathy understanding and patience, patience, patience. Lots of patience.’ (Alison)

Intuition is a term that can be used to describe the emotional exchange between people where there is no apparent evidence of explicit conscious reasoning. It is a form of implicit knowledge that appears to receive little consideration as a skill because it cannot be quantified. A further concept is tacit knowledge, which Schon (1983) describes as a form of knowing in practice but practitioners cannot articulate it verbally.

Professionalism as a DSW involves the ability to make sound judgements in difficult, complex and uncertain situations. A key example of this is when supporting service users with behaviour that is distressing, violent or upsetting to the worker and to the person themselves. ‘Their job demands not only physical strength but also artistry, intuition, skill, patience and finally affection’ (Dodson and Zinavage, 2007: 923). These skills are central to be able to do the job effectively but their intangible nature makes them difficult to identify or even teach. To some extent it is dependent on the character of the individual. ‘Care workers need to be open and receptive to reciprocal contributions to the care process that might not be immediately obvious’ (Barnes, 2012:80). The non-verbal skill paralinguistics uses cues from pitch, volume, intonation and intensity and was used by Collette when she spoke about a service user having ‘different cries’ and how she was able to respond more quickly to his needs as she had learned to recognise the subtle nuances to his tone.

‘I could tell if he was in pain or if he just wanted to be moved in the bed because he couldn’t move himself.’ (Collette)

In hospitals, nurses ‘internalise the norms of a professional code of conduct in order to meet the expectations of their colleagues and the public concerning the ‘right’ image of a caring professional’ (Bolton, 2008:20). Her observations of a hospital ward showed that nurses presented a ‘professional demeanor that distances them from distressing or over demanding elements of their caring work, but at the same time, they are emotionally present and fully engaged in the interaction order’ (2008: 24). This contrasts with theories of a ‘postemotional era’ where people no longer show their true feeling and wear masks in order to fit in with society (Bolton, 2008). ‘Workers are

expected to be authentically caring and empathetic or to embody it through deep acting whilst also maintaining professional distance and managing this contradiction in their performance' (Fabianowska and Hanlon, 2014:55). The workers I interviewed expressed these tensions because they were genuinely caring about the people they worked with and were bereft when a person they worked with for years died. They were able to manage this tension in their practice in how they reflected on their role as not-family.

'...it's hard to draw the line where it isn't your grief because they're not your family but you have worked with this person for years.' (Collette)

This quote is Collette's reflections on how grief is often viewed as the property of the family and not available to the worker despite their long standing relationship. In this case, the worker is unsure if her professional role allows for grief as she is expected to be able to manage these tensions. Doka (2002) uses the term disenfranchised grief to refer to grief where a person is considered to be not entitled to grieve. In this instance it is because the relationship is considered professional rather than personal yet the overlaps are obvious.

Social care differs from other professions because emotional labour is central to nurturing the emotional wellbeing of others (Fabianowska and Hanlon, 2014). People look for coherence and meaning in our consumerist society where the boundaries between public and private are blurred. The concept of emotional labour was discussed in the literature review and is central in the formation of relationships (Wharton, 2009). The effectiveness of the care and support given is largely dependent on the building of meaningful relationships and so requires engagement or investment at an emotional level. 'Research on caring occupations shows how changes in the structure, practice and professional norms guiding these fields have the potential to increase or diminish workers' positive experience of care giving' (Wharton, 2009:154). The worker must display emotions they do not feel while suppressing those they do feel. This may have a negative impact. 'Workers' sense of an authentic self is undermined, since emotions after all belong to a person's inner realm of self expression and feeling, and they become alienated from their inner selves and true feelings' (Bryman, 2004: 121).

Some writers suggest that you do not need to have any affection for the person you care for in order to give them the care they need (Barnes, 2012; Lynch & Lyons, 2009).



However, in general terms there is usually a connection between caring about someone and caring for them. A truly caring person must feel something for the people they are caring for and this means that the person receiving the care will feel they actually matter. ‘Emotion itself is often part of what makes the act morally right or appropriate in a given situation’ (Blum, 1980: 142). It is clear from this that emotions should be central to the caring relationship rather than just some form of added extra. Calhoun (1992) is critical of this idea arguing that emotions are prescribed and come from a social constructionist view of emotion. In other words, people feel emotions that are expected depending on their context e.g. sadness at a funeral. It is also worth questioning how being overly emotionally involved may affect care workers. The level of sickness, disability and death is naturally more pronounced in many caring environments. If a carer develops the emotional attachment promoted by Blum (1980) and mourns for every person they care for, they are likely to experience greater stress and burnout. By engaging in deep acting on a regular basis they are more likely to experience emotional attachments and greater intensity of grief than if they remain disengaged (Taylor, 2015). Some detachment may actually be more beneficial in care to avoid emotional strain. It is in essence a job where one cannot be emotionally deeply engaged with everyone but one must be sufficiently involved emotionally to understand what people are experiencing and be able then to respond appropriately to address needs. Almost all of the respondents stated that they were able to successfully separate work from home life and that when they were at home they did not think about work.

‘When I’m off I’m off. I don’t think about work.’ (Sean)

## **6.2 Time**

This section of my discussion will examine how the role of the DSW is constituted through a particular construction of time. Time is an abstract concept that is integral to our lives. Human beings originally organised themselves around the rising and setting of the sun and seasons but this gradually evolved to become more formalised. Since the industrial era, time has taken on the character of a clock, becoming mechanical, regular, removed from nature and viewed as a resource to be managed (Mulgan, 2005). We use tools such as clocks and calendars to synchronise, order and sequence our lives. Adam (1990: 95) wrote about the idea of ‘budgeting time’, which is ‘how clock time is experienced, structured, passed, rationed or allocated’. Time emerged in the interviews

as crucial in building relationships with service users. The word 'patience' featured a total of 49 times in the interviews and was most often used in relation to having the patience to take the time to get to know and build up relationships with people.

'It would definitely be over time. What I would do with people is build up a relationship first because a lot of the people, they're very cautious.' (Ruth)

In disability support work, it is difficult to plan particular outcomes as it is largely dependent on the pace of the person being supported. A typical morning routine usually takes longer for a person with a disability. It also became clear during the interviews that in order to promote independence time was needed to allow people to go at their own pace. There are clear benefits. 'Being independent helps to improve self-esteem and contentment enhances dignity and gains respect from others' (Aldridge, 2010:33). Emer talked in detail about the time invested in a person so that she would be able to make her own cup of tea without assistance. It is clear from accounts such as this that while initially there was an increase in use of time and resources to build up a relationship and then work closely to learn this new skill, the end result is beneficial because that particular person is now at a stage where no staff input or resources are required for her to make the tea.

'...we did this over and over and over again with her, trying with a staff there and now she's able do it herself.' (Emer)

Frequently throughout the interviews it appeared that the work was heavily dictated by the presence of the clock. Routine can be positive as it ensures certain tasks are carried out at an appropriate time and people's needs are met (Killeen, 2014). However, it quickly becomes a negative when it becomes restrictive. Respondents described their working day as marked out by the pressing demands of time. Houses are smaller and based in the community but respondents still felt bound by rigid routines, dictated by what Aoife (p.53) referred to as the 'clock in our heads'. This shows that despite the reduction in size, it is arguable that the fundamental issue, which can institutionalise living, is time. Designing a house to look 'homely' rather than 'institutional' is only part of the solution because it is the way such spaces are used that will have a much greater impact (Burton, 1998).

Time is often experienced as inadequate, restricted and rushed but this contrasts with less demanding times where it is more elastic and staff are able to promote values

associated with independence. An example frequently shared was around dinner time as it is less pressured and they can invest time in getting service users involved. Respondents' accounts reflected how they support service users to reach their full capacity when carrying out household tasks. Killeen (2014) comments that social care is about empowering people to take control of their own lives. This creates a conflict for staff when the level of impairment for some people requires care. They must get to know each individual and recognise areas where they can be supported to be independent but also identify where the staff must support people to develop the capacities they have (Kittay, 1999). This is different for each person. Respondents discussed how they manage this and adapt the level of support to each service user. This requires getting to know the individual and learning about their individual capabilities, which of course takes time.

The need to constantly have particular tasks completed by a certain time creates an unnatural environment not largely removed from institutionalised routines. Routines were originally deliberately used strategies in institutions whereas now they are what staff resort to in order to cope with limited time and resources. Institutionalisation can occur through shift patterns. Shift work is more intense and there is a longer time spent working with the same people (Coyle, 2005). It is important to provide for breaks in shift work. Some managers said that they design rotas based on EU directives. The EU's Working Time Directive (2003/88/EC) requires member states to guarantee basic rights for all workers including a rest break during working hours if a shift is longer than 6 hours. This does not appear to materialise on the ground for everyone as it contradicts the point made by Edel who said that she did not get breaks on a 13 hour shift.

‘...even if you could just sit in your car for twenty minutes and just take a breather cause no you don't get that at all.’ (Edel)

### 6.3 Professional identity

Professional identity is the view of the self as a professional plus competence resulting in congruence between personal and professional worldview (Reisetter et al. 2004). DSWs are socialized through observation, supervision, consultation and practice (O’Byrne and Rosenberg, 1998). ‘The term professional is used in relation to people who are trained to engage in specialist activities that meet standards as required by a formal professional body’ (Iacono, 2014:292). Social care workers can form a solid professional identity when they are in an environment, which fosters core values such as choice, inclusion, empowerment and dignity and supports the worker to apply these in practice. According to Bolton (2005), workers in the caring professions are motivated by an understanding of their role and have altruistic tendencies. Kittay (2005) questions how workers maintain their dignity and identity when they work in an environment where they must put aside their own needs and desires to fully attend to the people they support. ‘A critical concern for dignified and family-like care of one segment of our people does not justify sacrificing the humanity of another, in this case, those who do the job of caring’ (Dodson and Zinzivage, 2007: 924). White and Tronto (2004) argue that care should define the relationship but also provide space for the self to develop a separate identity.

Social care’s long history in Ireland has been detailed in the literature review yet it was only designated as a regulated profession in 2005 in the Health and Social Care Professionals Act. When talking about the impact of social changes, respondents talked about the positive changes for service users; their increased involvement in decisions affecting their lives; the use of goals to work towards and the improved standards in their living conditions. The values of the DSWs were consistent with the ideals of professionalism in social care as they discussed promoting empowerment, choice, social inclusion etc. However, it appears that with professional recognition comes increased regulation and standardisation. A key feature of policy is accountability and consistency, which has led to an increased volume of rules and procedures to standardise decisions in relation to care planning and needs assessments (Kirkpatrick, 2014).

‘...there’s a lot more emphasis on care plans, goals. There wouldn’t have been that much of an emphasis on it when I started 12 years ago...’ (Kelly)

Professionals spend more time recording and documenting and adhering to procedural instructions, which causes work intensification. There is little evidence to suggest that increased regulation leads to an improvement in services but rather the contrary is the case (Rogowski, 2010). Respondents revealed how reduced staffing and resources in addition to increased paperwork has detracted from their time with service users as they must spend more time completing forms and checklists than working with individuals. Regulation is considered essential to ensure standards are being adhered to and staff are working efficiently (Rogowski, 2010). A negative consequence of reductions in costs and increases in labour is that it contributes to workers losing their sense of identity as caring workers (Baines et al. 2014).

‘[DSWs] are employed within bureaucratic organizations and have to adhere to the regulations of the agency, which might conflict with what are seen as the needs of the client’ (Abbott and Wallace, 1990: 1). Cognitive dissonance is a perceived discrepancy between one’s own attitude and behaviours (Martin et al. 2013). This can occur when DSWs do something for a service user that they know they are capable of doing for themselves. The worker may manage this dissonance by recognising that time and resource constraints are forcing them to make decisions in their practice that are against their professional judgement. This could become more damaging if the worker begins to develop a new understanding of their role as someone who simply does things for the service user and applies this to every situation, not just those where time is limited. They reformulate their schema of what the role of a DSW is, thus forging a damaged sense of professional identity, which may have a negative impact on how they perform their duties in the future. Swain et al (2005) argue that the juxtaposition of the concepts of ‘independence’ and ‘individualism’ imply self-sufficiency and this can be very confusing for the service user as well as the worker. By redefining independence to encompass varying levels of choice and control in one’s life, it allows for a different understanding and is of particular benefit for people whose impairment limits their capacity for self-sufficiency. To this end, staff tailor their approaches to each individual’s needs and capacity.

The respondents’ draw upon commonly circulated ideas of caring to explain their identity. For some, you had to be ‘that type of person’ and for others you had to be ‘like a mum’. The tendency of workers to ‘naturalise’ emotional labour in this way serves to

devalue the emotion work (Taylor, 2015). There is a fragile complexity in continuously balancing kinlike and workplace relationships (Dodson and Zinbarg, 2007). This appears to have greater parallels with Nodding's (1984) perception that women are naturally more caring than men. It conflicts greatly with the assertion that workers should maintain a professional distance as it is in the best interests of the client (Harris, 2002). Because there is no agreement that distance is in the best interests of the client, being able to establish warm and trusting professional relationships are considered a prerequisite for effective work in almost all of the literature (Kay, 2013; Trevithick, 2012; Forster and Iacono, 2008). There appears to be an expectation on workers to behave in a paid context as they would in the private sphere while recognising provided in the provided in the private sphere can be neglectful or abusive.

For every kind of caring work in the public sphere, there is an analogue in the private sphere that hovers around like an inspirational doppelganger. Care workers and those they care for seem to carry images of this other sphere and use them to compare and judge the public sphere (Stone, 2000:94).

Although the time spent in education has increased, the connection between educational requirements and the skills in the job are essentially false (Edgell, 2010). In most cases, educational achievement outweighs those required for most jobs. Professionals are made to feel easily dispensable with the idea of 'someone else can fill your seat' (Hochschild, 1983: 99). Toynbee (2003) comments that the lower paid the job, the more likely employers are going to make workers feel that they should be grateful they have a job. A consequence of the recession is that employers can afford to phase out overtime pay and other such benefits because there is a surplus of unemployed people seeking work so positions are easily filled. Austerity measures and increased job losses in the current economic climate means workers are forced to accept changes or face unemployment (Morgan, 1999).

Public attitudes to people with disabilities may have been connected to fear or ignorance but now tends to reflect a tendency to blame the workers who are perceived to be abusing service users. Goffman (1961) talks about stigma, how elements of 'difference' can lead a person or group of people to be perceived as 'other'. He talks about the 'burden' on people living with a disability, managing social situations to protect 'normal' people from discomfort. DSWs manage challenging behaviour in public, an occurrence that would traditionally only have happened in the private institution.

Amanda described a situation where a service user sat down and started ‘screaming and kicking’. How the DSW addresses this in full public view can risk being misinterpreted and this challenges their identity as caring, nurturing people. This is particularly pertinent with the increased negative attention focussed on residential care homes following the Prime Time report on abuse in the Aras Attracta care home in County Mayo on 11 December 2014 and subsequent HIQA reports.

At any stage in life a person could develop an impairment through illness or an accident. People bracket off the sometimes unconscious fear that it could happen to them by creating separation between able bodied and disabled people (Wendell, 1992). This means they unwittingly contribute to social practices that are oppressive to people with disabilities. A negative social environment can be just as harsh for disabled people as an environment lacking in physical adaptations and supports (Nicki, 2001).

Respondents did not appear to maintain this perception of people as ‘other’. It was clear that staff valued service users and held them in high esteem. Staff forge a new identity where they are now public in their role and instead of hiding impairments; people are forced to challenge their perceptions instead. This is all the more pertinent in a society that promotes the perfect body image. Promoting independence means staff must adapt their view of people with disabilities. This shift in perception was evident in Claire’s (p. 55) account of ‘giving the responsibility back to the people’. She recognised that she was not in a role where she could control every aspect of their lives. This shows how the social context changes workers’ perceptions and a recognition of the reciprocal and more equal nature of the relationship. Aoife (p.55) talked about supporting service users to engage in part of a task such as holding a hairdryer while Stacy (p.55) promoted involvement for individuals with severe to profound impairments by having them present to watch her while she carried out tasks. This demonstrates changing attitudes where independence is not only defined by self-sufficiency but exists on a gradient determined by each individual’s capacities.

The increased workload has a negative impact on the experience of the job for staff but also on the quality of care and support afforded to service users.

‘Sometimes you feel there's not enough hours in the day. You're rushing and if you're out you're trying to get back. You're put on a time limit.’ (Fiona)

In the current economic climate, staff numbers are cut. Smaller numbers of people are worked harder and this means there is ‘more emotion work to be done, but fewer workers to do it’ (Hochschild, 1983: 125). Workers are now expected to do more work in less time to their own and the service users’ detriment. Toyne (2003) believes that lack of staff and time are the key reasons, service users may be ‘treated less than perfectly’, rather than through any intentional unkindness. ‘When asked to make personal human contact at an inhuman speed, they cut back on their emotion work and grow detached’ (Hochschild 1983:126). Fabianowska and Hanlon (2014) found that needle exchange workers use emotional distancing as a strategy to cope. The intensity of adrenalin and emotions is particularly felt during an incident where a person with a disability is distressed or violent in their behaviour. Staff have to make the most informed choice they can and respond immediately in the moment (Lyons, 2013). They must then work with the consequences of that snap decision. Respondents often described specific challenging incidents they experienced and how they managed it.

Burnout is a frequent outcome where workers must 'fake their feelings' in social care situations (Baines et al. 2014). Working as part of a team aiming to deliver effective care to another can be a challenging experience for social care workers. ‘In an ideal world, all the members of the team will feel supported, their opinions will be valued and respected, they will speak freely and they will understand that people will constructively criticize their work in a way that feels safe and helps them to learn’ (Lyons, 2013: 104). Social care work is demanding and this needs to be recognised during supervision meetings with structures put in place to support them (O’Neill, 2013). One manager, Miriam, recognised the importance of appropriate timing to provide support, how it is needed at the particularly tense time during and immediately after the incident.

‘It’s not just for when you pencil them in in the diary but having them when you need to have them.’ (Miriam)

It is difficult to maintain a strong sense of a professional identity when there is a perceived barrier between the staff and their managers. In the interviews, respondents spoke positively about the support they received from their direct line managers but this did not extend to managers above them in the organisation. They suggested they did not feel they would not be consulted by management and area managers appeared to focus



on inspections when they visited. Rather than recognition for their work, many workers experienced such occasions as overly critical.

‘It was kind of like ye can only see the one bad thing and no praise for all the positives that have been done.’ (Emer)

A greater emphasis is being placed on the monitoring and evaluation of staff performance, which makes supervision far more judgemental and inquisitorial in nature (Kirkpatrick, 2014).

‘...sometimes they work or they don’t work. Sometimes the debriefing can make you feel like you’ve made a mistake.’ (Ciara)

This may contribute to them feeling as though they do not have a valued part to play in the organisation. Devaluation of care obscures the capacity of the worker to effectively engage in the work (Barnes, 2012).

Twigg (2000b) is critical of the use of managerialist language when discussing care with an emphasis on effectiveness and efficiency while the daily realities of care were overlooked. Drawing on such terminology from accounting and economics is wholly inappropriate. Clearly care and support work, like any other form of paid labour needs to be effective in what it is intended to achieve and resources must be deployed to ensure such work can be carried out without undue wastage. However the complexity of relational work and the time required to develop effective work relationships is often overlooked in the allocation of resources. ‘The ways in which idioms of kinship are mobilized in relation to paid care work in particular contexts... can be revealing of underlying questions about the interdependencies, vulnerabilities, frustrations and power struggles as well as the more positive emotional connections, which caring involves’ (Kay, 2013:10).

### **6.3.1 The body**

Body work is low status work. In nursing, staff progress away from the basic body tasks of bedpans etc. towards more high skilled work: ‘progressing away from dirty work on bodies to skilled work on machines’ (Twigg 2000a: 390). Further, care of the body has now begun to transfer out of healthcare and the nursing sector into the hands of the unskilled care worker. This is mainly due to cost reductions but also reinforces the idea that care is low status work and thus must be transferred down the occupational

hierarchy. Despite the low status of bodywork, it is generally highly praised. Nurses and care workers are often regarded as almost heroic for doing work that most people 'could not do' (Twigg, 2000a).

Modern culture popularises the 'good body' (Featherstone, 1991) which is presented as perfect and flawless particularly in the media. This sits uncomfortably when faced with 'the negatives of the body - dirt, decay, decline, death' (Twigg, 2000b:393). It is these perceived negatives, with which some forms of care work is most involved. The tendency to present caring as feminine and maternal means that there is little recognition of the fact that it is still work (Lee-Treweek, 1998).

It is interesting that respondents did not go into detail about the bodywork. There appeared to be a distancing in their discussions as they merely listed tasks such as showering and dressing. 'Care Workers are on their own in these areas, their practice is rendered invisible, something beyond the limits of official discourse' (Twigg, 2000a: 400). It is implied that by not discussing the more embarrassing aspects of the care, they are adhering to an implicit rule identified by Haralambos and Holborn (2008) to ensure nudity between strangers is handled effectively. Sometimes they mention something specific, for example 'Michelle' mentions the strain on her back when she rolls service users in the bed to change them or 'James' mentions having 'every type of bodily fluid' over him but the avoidance of such details suggests they are protecting the dignity of service users.

'Accounts of care work... have tended to play down these bodily aspects, emphasising instead the social, emotional and interpersonal elements of care work, and avoiding direct reference to the less attractive parts of the body' (Twigg, 2000a:394).

Some forms of carework share the following characteristics; dealing with human waste, nakedness and direct touch. 'Avoiding direct language is one of the techniques deployed by care workers in negotiating the body taboos' (Twigg, 2000b: 401). This is not only to protect the privacy of the person receiving the care but also to protect the public esteem and status of the worker (Lawler, 1991). Body work is demeaning and embarrassing so it is performed 'offstage' to protect the caring image of the care worker (Twigg, 2000a: 405).

Respondents in the study frequently disclosed how their bodies were damaged as a result of the care work. Typically their back suffered wear and tear as part of the job. This creates some interesting parallels between the body of the staff and the body of the service user. The staff member goes into this line of work to care for imperfect bodies and over time their own body gets broken down in the process. This could be compared to the emotional connection of empathy but it occurs in a physical way. Freud and other psychoanalysts have devoted a considerable amount of attention to the psychosomatic connection between the human mind and body (Grosz, 1999). Transference, where the patient projects attitudes and emotions onto the therapist could be considered to manifest itself in a physical way. The physicality of care work combined with poor diet and habits causes the body of the staff to break down, effectively mirroring that of the service user. Work related stresses are connected to increased blood pressure at home as well as during work (Clays et al. 2007).

#### **6.4 Policy priorities**

‘The precise division of responsibility between public and private, state and family is a matter of ideological, cultural and political debate’ (Barnes, 2012: 61). The approach of staff in their work with service users continually changes based on current policies. While policy is essential for improving standards and the quality of service delivery, Sowerby (2010) observes that people with disabilities do not speak about policies but have a clear sense of the people who are supporting them in their daily lives. Tronto (1993) differentiates between caring for (i.e. attending to a person’s physical needs) and caring about (i.e. being attentive and responsive to the overall needs and welfare of the person). Post-enlightenment thinking emphasised reason and rationality in western cultures but a significant cost of this is a devaluing of the emotional aspect. In this respect, value is only given to the physical aspect of caring for the individuals’ bodies without giving due regard to their social and emotional needs. Thus, ‘care’ needs to be reconceptualised to encompass the emotional connection of a ‘shared accomplishment’ as opposed to the performance of practical tasks. (Thompson, 2009; Parks, 2010; Hall, 2011).

Empowerment has been popularized as a key value when working with disabled people but there is an ambiguity around its precise meaning. Dalrymple and Burke (1995: 48) ask, ‘Does it lack specificity and gloss over significant difference? ... Is it a much

abused and devalued word?’ One definition of empowerment is ‘having knowledge and the capacity to use that knowledge for increasing control over one’s life and resulting in improved quality of life’ (Gilmore and Kearns, 2009:131). Price (1990) asks what happens if the individual is only able to have partial participation in a skill. The respondents showed they were able to manage this effectively.

‘We have one lady who’ll put her hand out for shampoo and she can wash her hair with one hand and she’ll cover her eyes with the other. Another lady will dry under her arms to a certain amount and you’d help her.’ (Aoife)

‘All people have skills, understanding and ability’ and these need to be recognised and their potential maximized as far as possible (Braye and Preston-Shoot, 1995:49). Staff must be realistic about what people can do and have a positive attitude about the capacities they have to develop (Aldridge, 2010). Assessing how much a person can learn and where one has to complete a part or all of a task, especially if the other cannot clearly communicate requires attention to nuances of movement, and tone among others. The work is intrinsically relational and time laden. Staff support service users with tasks around the home including cooking, cleaning and laundry. These apparently simple everyday activities are actually very sophisticated as they involve time, skill, insight and good judgement. ‘Frontline workers use their professional judgement *and* agency to meet clients’ needs, rather than passively carrying out bureaucratic and self-protecting requirements’ (Green and Sawyer, 2010:377).

Promoting independence is often deemed an important part of their role by DSWs as it provides service users with an opportunity for a ‘normal’ life (Hawkins et al. 2011). Low staffing is a frequent measure used to reduce costs but this undermines the DSW in their efforts to offer individualised care and support as they are increasingly under pressure to keep up basic tasks (Dodson and Zinavage, 2007). They are frequently torn between the desire to allow service users to go at their own pace and the pressure placed on them to complete these tasks quickly. This leads them to make difficult decisions at particularly rushed times in the day, such as the morning. Kate (p.56) told how she got the breakfast ready for a lady she supported before she was out of bed just so she could be ready on time for her day centre in the morning. Edel (p.60) confided how she and her colleagues take risks such as lifting a service user on the bus despite the fact that a hoist should be used because they are so rushed. By deviating from standardised procedure, they run the risk of getting caught and being held accountable (Hawkins et

al. 2011). Working against health and safety regulations would have consequences for their position but respondents felt they had no other choice.

If it is claimed that workers do not have the time or opportunity to do other than offer the most perfunctory assistance, if practices are evident that if public would be condemned as care less, then these are political issues that require public debate to influence what goes on in such institutions and the level of funding required to support ethical care within them (Barnes, 2012: 77).

Service users are supported to exercise choice and control, which is facilitated through person centred planning. Person centred planning places the service user at the centre and the main people in their lives are involved in supporting them to reach goals, which they set for themselves. 'Individuals who exercise choice and control can realise their citizenship; their illness, disability or frailty is not an impediment to their participation in things like the work, leisure and cultural activities that constitute everyday life' (Barnes, 2012: 63). This is difficult for people with intellectual disabilities and often results in professionals continuing to make decisions 'in their best interests'. McLaughlin (2009) is critical, suggesting that service user involvement is usually 'tokenistic and unproductive' where their involvement has become more important than aiming for successful outcomes in their care and support. Discourses of choice and empowerment create mixed care economies, which create opportunities for private companies and lead to an increase in managerial power (Rogowski, 2010).

Social inclusion is a key element of disability policy and is particularly prioritised in deinstitutionalisation literature. The focus on person centred planning has enhanced the profile of social inclusion as it is frequently expressed as an aspiration by people with disabilities (McConkey and Collins, 2010). Disability support staff have a significant role in supporting service users' involvement in the community. Respondents were positive about this aspect of their role. Many service users in these settings are likely to have social, emotional and cognitive challenges, such as autism. People with such impairments frequently experience heightened anxiety when changes or disruptions to their own routines occur. As Sarah (p.57) commented, this creates difficulties for staff when they are attempting to support service users to divert from their routines and try new things in the community.

Staff working with people with mild intellectual disabilities are more likely to use a facilitative rather than a directive style and this is creating positive lines of

communication (Reuzel et al. 2013). This was evident when Claire spoke about ‘giving the responsibility back to people’. Rather than dispensing advice as an expert, workers listen to and support service users. Forster and Iacono (2008) argue that the greatest amount of knowledge around communicating with people with severe to profound disabilities lies with the disability support worker as they overcome various barriers to communication: within the self as a DSW, the staff team, the agency and wider society. In their study, they found that touch, attachment and playfulness were all key tenets to create meaningful interactions and form genuine relationships with service users.

### **6.5 Managerialism**

It is not enough to consider the relationship between frontline workers and service users but also the culture of the agency within which, these relationships exist (Barnes, 2012). A top-down paternalistic management system will likely have an impact on the way workers interact with service users. Problems can emerge when care is viewed as a commodity that can be bought, rather than a process where needs are communicated with care and support provided within a reciprocal relationship. ‘Managerial practices that concentrate on developing systems, procedures and rules, rather than on enabling the competent practice of care giving, cannot support good care’ (Barnes, 2012: 70). Cost effectiveness is valued in neo-liberal economic discourse and where this prevails, it will guide social care practice rather than a value base associated with humanitarianism (Healy, 2005).

It is apparent that there are clear benefits to having time to build relationship, work slowly and invest in service users. However, this emphasis is not reflected in a time of austerity where staff hours and wages are increasingly reduced. Caring professions are ‘undervalued financially’ (Hutton and Jones, 2005: 99). There appears to be a distinct lack of value placed on the relational aspect so time is not allocated to this work. Instead, an emphasis is placed on tasks that are visible and measurable.

In the Western dichotomy between reason and emotion, work is viewed as belonging to the realm of rationality. Its purpose is to get things done, to produce something useful or desirable to somebody else, and to meet specific goals (Stone, 2000:99).

The increase in strict standards and regulation from the Health Information and Quality Authority (HIQA) has led to a greater workload with record keeping, stock checks,

medication checks and cleaning requiring more and more of staff time (Killeen, 2014). Respondent's frequently discussed the increased amount of paperwork required in the job. Goffman's (1961) observations of institutions showed how every aspects of the 'inmates' life from birth until death is documented and arguably little has changed in this regard. It can be argued that this leads to the creation of increasingly bureaucratic environments.

Bureaucratic restrictions and lack of resources often leads workers in care environments to give priority to physical, visible tasks than the emotional work of caring, which is more difficult to measure (Foner, 1995). This resonates with Goffman's (1959) observation that nurses are perceived to be wasting time unless they are seen doing visible tangible tasks, such as administering medication. The respondents in this study were strongly aware of the increase in such visible, tangible tasks as paperwork and checklists and recognised that this forced them to compromise on their time with service users. 'In short, time is saved, work allocation is rationalised and the personalising activities... are squeezed out' (Aronson and Neysmith, 1996: 67). Value appears to only be placed on the physical act of caring for the service users' bodies with little regard given to the social and emotional aspect (Parks, 2010).

The increase in responsibilities means staff time with service users is compromised. Staff time is allocated to tasks such as personal care and paperwork, while the relational context wherein these tasks are carried out is ignored. Time spent chatting with service users is considered 'wasted money' in a market where efficiency is emphasised and costs are cut (Diamond, 1992). This affects not only the physical tasks that need to be completed but also the emotional work. Nurses are less likely to provide emotional support to patients when time is scarce as they must focus instead on physical caring tasks (Pearcey, 2010). Task oriented approaches emphasize efficiency, which is assessed based on completed tasks. This is worrying considering the clear part relationship has to play in disability support work. Staff are faced with 'the constant conflict between humane standards on one hand and institutional efficiency on the other' (Goffman, 1961: 78).

Insofar as building trust takes time, it is often time in which the more physical and countable tasks do not get done. But while individual caregivers may have the patience for this long, slow build up of trust, organizations usually do not. They

have work to get done, they pay the people to do the work, and time is money to them (Stone, 2000:103).

Managerialism, also known as new public management, is a form of management most closely associated with the rise of neoliberal policies across most of the western world over the past 30 years. The core principles of neo-liberalism are ‘less state, more market, more individual responsibility’, and in relation to the re-organisation of social services they are translated into the demands for deregulation, privatisation and flexibilisation (Lorenz 2005). It provided a basis for recreating social care to be more effective, efficient and accountable (Baines et al. 2014). It was adopted by the Irish government from the 1990s onwards to promote neoliberal economic and social policies (Lynch et al. 2012). This and other similar models have led to an increase in the volume, pace and intensity of work and a decrease in the aspects of care that contribute to dignity, fairness and equality in the workplace (Cunningham, 2008). Managerial practices that concentrate on developing systems, procedures and rules cannot support good care (Barnes, 2012).

Dustin (2007) makes the comparisons between social care work and Fordism. Fordism is characterised by reductions of cost and waste, increased standardisation, greater work intensity and the use of targets and outcomes (Armstrong and Armstrong, 2002). Fordism is essentially an older version of managerialism, which is the focus of this discussion. It is not far removed from the Weberian ‘ideal type’ for bureaucracy (Weber, 1964) with the increased emphasis on speed and efficiency ensuring that tasks are performed uniformly in the right time and place. This approach has its advantages to ensure transparency and prevention of abuse but the emphasis on formal directives could quickly cause a return to institutional living (Foner, 1995). Individuality, spontaneity and autonomy become suppressed with people being viewed as mere ‘cogs in a machine’ (Giddens, 1971: 216).

The need to act in a caring, nurturing role contrasts sharply with pressures to complete tasks on time causing an uneasy tension. ‘They are expected and often sincerely want to be responsive to patients’ individual needs and problems. But administrative rules can prevent them from offering this kind of supportive treatment’ (Foner, 1995: 231). This is evident in Sinead’s (p.53) assertion that everything is too ‘by the book’ causing her to feel restricted in her freedom to make decisions. Working within a value based system



with a particular client group may be thought to compensate for difficult work conditions and lower wages (Nickson et al. 2008). This is repeatedly reported as what attracts people to work in the non-profit sector (Baines et al. 2014). However, employers often exploit the inherent satisfaction gained from such work as an excuse not to pay suitable wages (Taylor, 2015).

The idea that professionals are untrustworthy and need to be controlled and regulated is a tenet of managerialism. Therefore, strategies must be used to extract the maximum amount of labour from them (Dustin, 2007). Professionals must work harder and be more productive. This of course contrasts sharply with the largely unpredictable environments described by respondents. People across the human services sector are being expected to become more effective and efficient, forcing them to manage and organise their work with administrative and managerial processes, which appeared to be viewed as more important than the people operating them (Coulshed et al. 2006).

Managerialist organisations are characterised by smaller production runs and a reduction in large centralised structures (Ritzer, 1996). Standardised work routines have been replaced by more flexible work patterns, such as short-term contracts or part-time work (Dustin, 2007). Within managerialist units, the job is fragmented into parts, which deskill the workforce e.g. care assistants have basic responsibilities for care but not for overall input to the agency. In this, workers are only responsible for a portion of the whole process of service provision and managers gain power as they are the only ones with a view of the overall process (Ritzer, 1996). This can also lead to a lack of understanding as was evident when respondents said that they received no recognition and were never consulted.

A study by Ravetz (2000) found that while health managers were attempting to streamline nursing practice, they failed to see the complexity involved in certain tasks and actually reduced the effectiveness of the service provided. They observed that senior nurses bathed patients on admission to hospital so transferred this task to junior nurses, perceiving this a misuse of skill. However, it emerged that during the bathing process, senior nurses were dually carrying out an examination on the patient's body for physical injuries, bruising etc. This has implications for quality and safety as specific injuries might not be found in patients. It also decreases efficiency as the senior nurse must now examine patients at a separate time.

### **6.5.1 The impact of managerialism in disability support work**

The implementation of neoliberal ideologies has led to a compromised service quality in Finland (Miettinen and Teittinen, 2014). Reduced staffing has hampered the efforts to fully address the individual needs of service users. Strict time pressures leaves staff able to do little more than provide basic maintenance. Further, cost effective measures mean services are provided based on availability rather than suitability for individuals. Tronto (2010) fears that the commodification of care will lead to a narrowed focus on to basic care giving rather than a full understanding of the process of care, being attentive to individual needs and allocating responsibility for work to enable people to live independently. There continues to be a paradoxical struggle between deskilling and re-upskilling in care agencies (Carey, 2007). Even the way knowledge is imparted can be contested. The provision of regular training and the promotion of continuous professional development imply that workers are being upskilled. A range of qualifications from FETAC to degrees are accepted to be employed within the sector. However, an increasingly limited budget means that only basic training is being provided by agencies. One could question how a deskilled DSW can effectively support service users to enhance and develop their skills. Managers are also deskilled due to excessive bureaucracy and intensified work (Dustin, 2007).

It can be argued that managerialism has somewhat hijacked the moral imperative many women feel to do care work. It was traditionally taken for granted that care was an unpaid female activity but the surge in women leaving homemaking for employment led to an increased need for paid care providers. However, it is still a social assumption that care workers are self-sacrificing mother figures (Dodson and Zincauge, 2007). Women dominate in social care roles and are frequently employed on a part time basis. This reflects a societal attitude that women want part-time work to combine it with caring responsibilities at home (Skinner and Robinson, 1988). Women are overly represented in caring professions because of society's tendency to link femaleness to familial altruism (Badgett and Folbre, 2001). Emotional, relational work is typically left to women, while men take care of rational, practical tasks (Thompson, 2009). The notion that care is intrinsically rewarding (Noddings, 1984) is rejected by most feminists, arguing that it is no more enjoyable or fulfilling than any other type of work but can often be difficult and frustrating in equal measure (Badgett and Folbre, 2001).

Recognition for this field of work is slow because it is still imbued with notions that it is natural to women. This makes it difficult for DSWs to maintain a strong identity as a professional. They appear to be devalued externally by managers above them who do not recognise their position as a professional. Gendered expectations are prey to such misrecognition. The expectation of women to provide care regardless of work conditions or wages reflects the gendered social construction that women are naturally caring and altruistic. Representing care as predominantly women's work affects how care is valued in society (Green and Lawson, 2011). The stereotypical expectation of women to care has reinforced long shifts, self-sacrifice and unpaid overtime under a gendered ideal of altruism (Dominelli, 2002).

The undervaluation of care provides a political rationale to reduce welfare provision and impacts negatively on other policies related to social support (Staeheli and Brown, 2003). Women's roles as carers can be manipulated to serve the interests of those in more powerful positions (Barnes, 2012). However, by framing the work as nonmarket motivated allows for the justification of poorly paying staff. 'Tying employees emotionally to the organisational culture to create a sense of meaning and attachment for them are among the main mechanisms for creating that bond' (Bryman, 2004: 104). Debates around commodification of care can make it all the more difficult for workers to challenge low pay and poor work conditions, yet it has been shown in a study by Dodson and Zincavage (2007) on work practices and relationships in nursing homes that authentic care can actually be purchased and this was complemented in my findings.

Ideally, disability support services should be needs led (i.e. service user orientated) but austerity measures means they are increasingly service led and managerialist in nature. The managerialist search for the greatest efficiency with an emphasis on standards, competencies and routinized practices has been imposed on managers. While managers take responsibility for assessing, purchasing and reviewing, the worker provides the actual service. Line managers are often positioned as 'buffers' between funders, senior management, frontline staff and service users (Baines et al. 2014). The managers interviewed discussed the challenges they faced in light of continuing cuts to their budget. They are aware that they have little control over decisions made on a governmental level. They recognise the issues encountered by staff and refer to the

mounting number of tasks such as report writing and completing checklists. They also revealed how staff hours are being reduced and they now have less time to do more work and this confirms findings from staff interviews. They recognise that this leads to a reduction in the amount of time staff have to spend with service users and Rita (p.64) further believes that the social model is not being upheld in practice as repeated reductions in funding make this largely impossible, which has a negative impact on service users. Neoliberal ideals do not embody an understanding of the emotional, social and relational nature of human interdependencies that are necessary to ensuring practices that respect not only the recipients of care but also both paid and unpaid caregivers and the relationships between them' (Barnes, 2012 :65).

Tronto (2010) identifies reduced staff, inadequate resources and standardisation as characteristic of an institution that does not provide good care. It resonates with Hall's (2011) assertion that smaller supported living settings are a new institutional form with bodies to be managed and treated within them. This is indicative of how things change in their forms but perhaps not in their substance. Baines et al. (2014) argue that the ethos and missions of the non-profit sector are more aspirational than what is actually seen in practice. Although they are clearly outlined at a policy level, respondents' experiences of applying them in practice are limited due to a lack of funding.

Deinstitutionalisation and the move towards supporting people with disabilities to live in the community is a measure that was originally motivated by choice, individuality, 'normalisation' and emancipation. The focus, however has shifted to be more about cost as is evident in the *Value for money report* (2012) published by the Health Service Executive. The focus of this document is on cost effectiveness in the financing of disability services with managerialistic terminology throughout. Congregated settings, communal sites and organisations are under pressure to either close or change their methods of provision in the light of a rapidly changing socio-political and financial landscape. With the closure of communal spaces, the home is increasingly viewed as the best place to provide care as the individual is viewed as the appropriate scale of caring. The emphasis is on supporting people with disabilities to live, work and have leisure in 'normalised' and appropriate places. The support worker maintains them in a 'real' job and accompanies them to recreational venues that are not segregated as special. They live in 'semi-institutional spaces within mainstream communities' (Hall, 2011:592).

Frequently, when discussing empowerment, concerns about risk and liability hinder this process (Alaszewski et al. 1999). This appears to resonate with Sinead's (p.53) perception that she cannot do anything with a service user that is not in their care plan. In disability support work, potential future hazards are protected against in policies and procedures but this has the negative effect that it limits autonomy for staff. Beck (1992) suggests these risks are infinite and unsatisfiable, inducing fear of catastrophe. In disability support work, this has created a shift towards more tightly regulated and sometimes more risk averse approaches in decision making (Kirkpatrick, 2014). Increases in accountability and in adherence to policies and procedures results in a diminution of staff autonomy and creativity and has negative effects on staff morale and services users' experiences. In a study of the ethical dimensions of elder abuse (Ash 2005, cited in Barnes 2012:68), one manager observed 'all this activity that goes on often doesn't seem to get to the heart of how people are living and being cared for'. The constant battle to avert risks can have a negative effect on staff autonomy and freedom for service users to make their own decisions as they may be overruled due to overly stringent risk plans.

## **Conclusion**

To conclude, this chapter has explored key issues in disability support work as experienced by workers in the west of Ireland. It has explored interweavings of professional relationships and identity and the effect of policy priorities and the concept of time. Time and resource constraints impact negatively on their identity as caring professionals. Current neoliberal ideals are influencing models of disability support with the promotion of independence and individualism. Cost effectiveness, speed and efficiency are impacting on the experience of the job for staff. The next chapter will reflect on the overall study and provide concluding statements and recommendations.

## **Chapter 7: Conclusion and recommendations**

This study set out to enhance the visibility and attribute value to the experience of the Disability Support Worker in Ireland. My interest in this study developed from my own experience working as a DSW. The study provides an insight into current theoretical perspectives and tracks the journey through historical approaches to present day models of care and support for people with disabilities. It explores contentious topics such as the gendered nature of care and questions the symbolic influence of language. It highlights the centrality of physical and emotional labour for DSWs and the overarching necessity to provide them with appropriate support. The key questions this research sought to answer are applicable to their experience and interpretation of their role; contextual influences and theoretical perspectives; challenges they face and support afforded to them. In-depth semi-structured interviews with Disability Support Workers and their managers provided a range of invaluable insights. The findings from the fieldwork corroborate the data from the literature review and in turn, raised a number of issues, which were discussed in chapter 6.

This study sought to understand how disability support workers interpret their role and construct their daily experiences in their working environment. DSWs define their role in terms of their relationships with the service users and how they maximise the policy of person-centeredness. Their professional identity is founded in the relationships they have formed with service users, an element they deem essential to work effectively together. However, gendered expectations still exist as an undercurrent for workers. This inadvertently places them in a low status position, where they are not consulted and their work unrecognised.

The study set out to identify the challenges experienced by disability support workers and how are they supported at an organisational level. The main challenge is that the work is physically and emotionally demanding. Amidst a climate of increased austerity measures, DSWs work in an environment where staffing, funding and resources are continually withdrawn from services. The consequence of this is that they are rushed and stressed. In addition to this, the level of support afforded to them appeared to be lacking and somewhat dependent on the discretion of individual line managers.

I sought to examine the current legal and policy context in which disability support workers operate. It was necessary to begin by exploring approaches from the past to be better able understand current ideologies. Policies are increasingly focussed on promoting person centred values; Independence, choice and personal control. These influence how services are structured and financed but particularly impacts the DSWs who must learn and adapt quickly to the most current forms of best practice.

The final aim of this study was to identify the contribution of relevant theoretical perspectives to a greater understanding of disability support work. In this respect, the perspective of disability activists, such as Shakespeare (2006) was pertinent to better understand how they want to be supported. Theorists such as Trevithick (2012) and Barnes (2012) provide strong foundations for best practice while Twigg (2000) and Toyne (2003) allowed me to maintain a sense of realism with regard to the physical and emotional aspect of the job and even its status as 'dirty work'.

The methodology was designed with the intention of developing an insight to the experience of the worker. Observations were considered a particularly effective tool to immerse into the culture of each setting and identify issues that workers may not verbally disclose. Access issues meant that it was necessary to reconsider my method. In-depth qualitative interviews were used as a suitably effective alternative. Their insights were largely congruent with findings in the literature.

There is scope in future research for exploring the role of the DSW and how they conceptualise their role. Future research could focus on developing new models of best practice that encompass the perspective of the worker as well as the service user. It should also embrace relationships as a key factor of the emerging professionalism for DSWs. Training for workers could be reformulated to encompass this important aspect, which is crucial in developing person-centred services. DSWs continue to work at the frontline of services so the primary consideration should be the professional relationship and how this can be maximised. The impact of austerity measures and an increasing reliance on a managerialist approach is a key determinant of the staff/service user relationship. A relational understanding of care/support is crucial to ensuring the time and skill necessary to enable people to exercise choice and live well in the community to which we all belong. The analysis of professional experience offers rich opportunities for researchers to develop creative and innovative methodologies to further deconstruct

and understand the role of the disability support worker. Thus improving our understandings from the perspective of the DSW and the disabled person can lead to the creation of a strong professional identity in the sector and contribute to a positive culture of person centeredness. The findings from this study will contribute to a small body of research, which develop knowledge and understanding of the DSW in Ireland.

Future policies should incorporate and give due recognition to the voices of workers in the field. Their role should be suitably acknowledged. It is clear that their position working at the frontline means that they know and can identify the needs of the people they support. Therefore, their perspective should be represented at policy making levels within the disability sector.

It is also worth recommending that greater access to agencies should be allowed for researchers. Currently it is almost impossible to enter and research the experiences of service users and in my case it was not even possible to observe staff when service users were present. Whilst it is important to protect service users' privacy and confidentiality, there is also a necessity to have reasonable access to gain a more comprehensive insight and hear the voice of people at the receiving end of services.



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