# A comparative analysis of the governance mechanisms in two Centres for Inclusive Living that enhance disabled peoples' life choices

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# Declaration

I declare that none of the work contained within this thesis has been submitted for any other degree at any other university. The contents found within this thesis have been composed by the candidate: Dianne-Dominique Theakstone.

# Acknowledgements

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# Abstract

This study examined disabled people's access to independent living in Scotland and Norway. At the time of the field work for this research in 2012, the literature revealed no comparable social enquiry combining the concepts of citizenship, independent living and governance. Within disability studies, independent living denotes a perspective that recognises the interconnected nature of life areas that affect lived experiences of disablement and inclusion of disabled citizens. From the independent living movement, Centres for Inclusive Living emerged as unique governance structures with full service-user involvement and run by disabled people for disabled people.

This study focused upon to what extent the organisational governance structures in the Glasgow Centre for Inclusive Living (GCIL) and Uloba Centre for Independent Living (Uloba) in Norway facilitate or impede disabled people's access to independent living. The methodology adopted a mixed methods approach. The central method involved organisational case studies with GCIL and Uloba. This enabled an in-depth qualitative exploration through semi-structured interviews with the case study employees, service-user/co-owners and key experts within each country. In addition, an online survey was distributed to other organisations that operated within the disability field.

The analytical framework used an integration of the social relational model of disability (Thomas, 1999) and meso level governance analysis (Lowe, 2004). The social relational model of disability provided structural (macro) and agency (micro) level interpretations and an emphasis on psychosocial elements of disability. It

also enabled the synergy of a theory of impairment alongside a theory of disability. Meso (organisational) governance analysis focused attention on the connections between organisations in society. This focus revealed the lateral relationships with other meso level bodies, macro institutions and micro individual action.

Research participants prioritised the areas of peer support, accessible housing and personal assistance. Peer support was found to take both informal and formal manifestations and acted as a foundation for the other two areas of independent living. The findings highlighted that Centres for Inclusive Living provide facilitation for access to independent living across macro, meso and micro tiers of society. In particular, empowerment, peer support and user led governance formed key strategies that enhanced disabled people's access to independent living in Scotland and Norway.

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# Chapter 1. Setting the Scene

*Rolling past a pane of glass*

*The reflection I see is you not me*

*Legs immobile, body straight, my wheelchair frames myself*

*But right behind me is your face*

*A spectre hovering over my space*

*I stare, you blink, I turn around, until we face on common ground*

*"Hello" you say, and "How are you?", But more is there, words long past due*

*Unspoken looks still cast their spell,*

*The reflection I see of words unsaid.*

(Ruth Horrigan, 2015)

Ruth Horrigan's (2015) poem captures a sense of the historical entrenched nuances that surround the concept of disability. Horrigan alludes to the unspoken and pervasive attitudinal prejudices that portray the significant power imbalances within everyday interactions between disabled and non-disabled individuals. Such everyday interactions are reflections of societal practices whereby throughout history, disabled people have been denied control over their lives. The inspiration for this international comparative study came from my lived experience of disablement, and observations that certain practices or policies acted as barriers or facilitators to independent living for disabled people in Scotland. I was keen to investigate whether similar lived experiences of disablement and policies and practices existed in a different country, and selected Norway as a comparison.

This opening chapter to the thesis outlines the inspirational context that motivated my research into disabled people's access to independent living in Scotland and Norway. My biography as a self-identified disabled early career researcher also gave rise to reflections on developments within the areas of disability studies, citizenship and governance. For example, I was drawn to the social relational

model of disability as outlined by Carol Thomas in 1999. In contrast with the influential social model of disability (Oliver, 1990) in the UK, the social relational model emphasised the interplay between structural and agency level factors in the analysis of disablement. Nearly twenty years on, part of my objective in this thesis was to explore whether the social relational model remains relevant to disability research.

Figure 1.1 provides a brief glossary of terms used in this study, and is drawn from the language of the social relational model of disability. For example, within the theoretical approach this study uses the terms 'disabled people' as opposed to 'people with disabilities', and 'Disabled People's Movement' as opposed to 'Disability Movement'. The former rejects medical or social scientific constructions that divorce people from the experiences of disablement and instead recognises the social, economic and political restrictions placed upon people with impairments. The latter concurs with Oliver and Barnes' (2012) assertion that the Disability Movement refers to what they call a 'ragbag' collection of organisations and charities that are neither democratic nor a movement. The Disabled People's Movement, by contrast, places the emphasis upon user-controlled governance and services.

Similarly, I was aware of the contributions made by another disabled feminist, Jenny Morris, to the analysis of citizenship. Morris (2001), for instance, supported an ethic of care whereby society recognises the embodied emotional investments bound up in social care relationships. However, one of the strengths of conducting this thesis was the opportunity to expand my understandings, particularly around disabled people's sense of citizenship. For example, the work of Angharad Beckett (2006) emerged as a significant influence upon my thinking throughout the thesis.

Before embarking upon this research, my background was in housing studies. Housing studies' literature introduced me to the concept of governance. In particular, I was drawn to user led governance, following earlier research on the effectiveness of the Home2Fit resource (Scottish Accessible Housing Register) run by the Glasgow Centre for Inclusive Living, and the ways user led governance facilitates empowerment of disabled people. Additionally, Lowe's (2004) focus on

meso (organisational) governance analysis provided the inspiration to explore a potential complementary integration with the social relational model of disability (Thomas, 1999).

**Figure 1.1 Glossary**

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**Accessibility:** the degree to which information, a service or a device/product is available to as many people as possible, including people with different impairments.

**Barriers:** those things that prevent a person with impairment from being able to get to, or use, information, services or devices/products.

**CIL:** Centre for Inclusive Living that is run by disabled people for disabled people.

**Co-owner:** refers to users of Uloba (Norway's Centre for Independent Living).

**Disability Living Allowance:** non-means tested, non-contributory benefit for disabled people under 65 years of age, which was introduced in 1992 and was due to be phased out during 2013-2016, to be replaced by Personal Independence Payment.

**Disability:** how impairments affect someone's life; this is determined by the extent to which society is willing to accommodate people with different needs.

**Disablement:** refers to the economic and social processes that ultimately create both impairment and disability. It is mediated by personal experiences of impairment, politics of disability and societal responses.

**Doubletick:** a non-legally binding scheme whereby employers sign up to ensure that disabled job seekers, who meet the minimum criteria, are guaranteed an interview.

**Good practice guideline:** also known as best practice, refers to a method or technique that shows superior results to an alternative approach, and is often used as a benchmark.

**Impairment:** difficulty in physical, mental or sensory functioning.

**Inclusion:** the practice of ensuring that people feel they belong and are able to participate in community life, which includes accommodating any person with an impairment.

**Independent Living Movement:** originated in Berkley, California during the 1970s and campaigned for disabled people's equality in all areas of life.

**Intellectual disability:** a reduced intellectual ability and difficulty with everyday tasks; the term 'mental disability' is similar, but can include mental disorders such as depression or schizophrenia. Other terms used for intellectual disability include 'learning disability' and, previously, 'mental handicap'.

**Mobility impairment/locomotion impairment:** difficulty with walking or moving around. People with mobility impairments may be wheelchair users or use crutches, or may need extra time or support from another person to move around.

**Municipality:** Norwegian equivalent of a local authority in Scotland.

**Sensory impairment:** visual and/or hearing impairment.

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Source: Author

This thesis explores the concepts of independent living, citizenship and governance. Previous research has combined some of these concepts. For example, Prior et al. (1995) discuss the ramifications of a neo-liberal welfare distributive framework for disabled people's citizenship outcomes, whilst Sandvin's (2003) cross-generational study in Norway examines the changing nature of the disabled self and the links with disabled individuals' perceptions of welfare entitlements and personal rights. However, there is a lack of empirical studies combining all three theoretical concepts.

The theoretical approach for the study builds on the epistemological and ontological postulations that are most closely aligned to the social relational model of disability (Thomas, 1999) adopted by this study. This research incorporates an agency/structural analysis in order to combine theories of impairment with theories of disability (Abberley, 1987; Goodley, 2011). Disabled people are viewed as the 'knowers' of knowledge on the psychosocial factors that affect their lived experiences of disablement. In addition, the analysis of structural barriers aims to shed light on policies and practices that impact upon disabled people's access to independent living.

In order to integrate analysis of governance and disability, Lowe's (2004) meso (organisational) governance analysis was used in conjunction with the social relational model of disability (Thomas, 1999). This approach emphasises the role of meso level organisations within societies and the interactions they can reveal between national actors, laterally to other meso level bodies and to micro (agency) level lived experiences of service users. For instance, the Derbyshire Centre for Inclusive Living (which later became known as Spectrum) is a meso level organisation that interacts with micro level actors. The Derbyshire CIL drew upon service user perspectives and identified 7 Needs of Independent Living, which was later extended to 12 Pillars of Independent Living (Spectrum, 2016). Therefore, meso governance analysis, alongside the social relational model of disability, may provide cross-tier insights into the interconnections between individual action, user led organisations, policy and practice.

The research findings reflect priorities identified by participants. For example, peer support acts as a foundational component in other areas of participants' lives. Accessible housing and personal assistance are explored in-depth as examples of lived experiences of independent living and the ways that peer support acts as a foundational facilitator in both cases. Additionally, participants' narratives highlight specific policies and practices that facilitate or hinder disabled people's access to independent living.

The findings may help to inform future facilitation for independent living. Organisational (meso) level facilitators enhance disabled people's access to independent living in Scotland and Norway, and stimulate connections to aid access to independent living across macro (national policy making), laterally at a meso level and at micro (agency/individual) levels.

The findings from this thesis corroborate Roulstone and Hwang's (2015) comparative study of Sweden and the UK. Roulstone and Hwang's (2015) social enquiry was conducted post-field work for this study and highlights that at a meso level, Centres for Inclusive Living are best placed to identify and respond to the needs of disabled people across the 12 Pillars of Independent Living (Spectrum, 2016). This echoes Walmsley's (2000) argument that voluntary entities create an effective conduit between the state and individual service users. For example, the organisational case study participants in this research demonstrated that national allocation of resources controlled by Centres for Inclusive Living, or directly by disabled users, created an effective strategy to address existing barriers to independent living.

This research provides an insight into the governance structures that enhance disabled people's access to independent living in Scotland and Norway, filling a gap in knowledge and understanding of policy and practice. On one hand, the research produces a key contribution towards disability theory, and on the other hand, reveals a contribution towards practice. Firstly, the integration of the social relational model of disability (Thomas, 1999) with Lowe's (2004) meso governance analysis enabled the examination of disablement across agency, meso and macro

tiers of society. Uniquely, this brought together theorising of independent living, citizenship and governance in one study.

Secondly, peer support, one of the 12 Pillars of Independent Living (Spectrum, 2016), emerged as a fundamental cohesive force for the areas of accessible housing and personal assistance. This has practical implications for Centres for Inclusive Living and further investigation could examine the relationship between peer support and the remaining nine pillars of independent living, as well as assess the most effective conditions or measures that would nurture peer support networks among disabled people.

The findings of this study suggest future research or scope for practical solutions. A significant contribution from this study was the international comparative analysis of disablement. Neither Scotland, a liberal welfare regime, nor Norway a social-democratic welfare regime, were found to provide disabled people with full citizenship and rights to all areas of life. Future research could explore to what extent countries with similar and alternative welfare models enable disabled people's access to independent living, as well as identify whether the meso facilitators uncovered by this study can be viewed as applicable in any welfare typology. As Beckett (2006) asserts, regardless of the number of enhancers for independent living that might be put in place, societal attitudes across all tiers of governance need to recognise and support the personhood of citizenship.

Overall the thesis is divided into eight chapters. After this opening introductory chapter, Chapter 2, The Research Terrain, presents the literature review and sets out the conceptual framework. Chapter 3, The Research Journey, sets out the methodological approach adopted throughout this study. Chapters 4, 5 and 6 present the findings under headings of Peer Support, Accessible Housing and Personal Assistance - and highlight participants' narratives in relation to each of these pillars of independent living. The discussion in Chapter 7, Future Facilitation for Independent Living, brings together the key contributions made by this thesis. Chapter 8, Conclusions, presents the potential scope for future social inquiry and practice.

# Chapter 2. The Research Terrain

## 2.0 Introduction

This chapter presents the literature review around the topic of disabled people's access to independent living in Scotland and Norway. As Bryman (2008) noted, the research process is often depicted as a linear sequence: literature review, data collection and analysis and research outcomes. This study adopted Layder's (1998) adaptive theory in order to implement the social relational model of disability (Thomas, 1999). The emphasis is placed upon uncovering both structure and agency level issues in relation to the topic.

Norway was selected as the main comparator case study with Scotland, based upon its contrasting social-democratic welfare system, contrasting housing system, the recent interest from the Scottish Government in the Nordic model of governance (Scottish Government, 2014) and Norway's links to the social relational model of disability (Tøssebro, 2004), which has driven the Nordic lead in the area of independent living.

This chapter is divided into three sections. The first section, Disability and Independent Living begins by outlining the historical development of the social concept of disability. Examination of the evolving definition of disability illustrates how the combined ethos of capitalist efficient labour production and the rise to power of clinical medicine created and perpetuated a category of disability issues connected with the notions of welfare and work. The ways in which this definition led to concerns around genuine and artificial disability which fuelled the subsequent development of early welfare policies are explored.

The discussion continues by examining the origins of the concept of independent living and its inclusion into social policy after the Second World War. This section concludes with a review of disability theory and presents the social relational model of disability (Thomas, 1999), which is regarded as introducing contemporary theorising in disability studies. It discusses the challenges to clinical medical definitions of disability and, in particular, presents the strengths of this model.

The second section, What is Citizenship?, focuses attention on the concept of citizenship and develops this in relation to disability and independent living. The opening section begins with the history of citizenship, which outlines the key theoretical developments that have shaped current understandings of this notion. This is followed by a discussion of the criticisms put forward against a potential future of disabled citizens under current neo-liberal frameworks.

The section concludes with consideration of rights-based[1] perspectives to citizenship and presents the main challenges from a disability perspective to the notion of citizenship. It draws upon the work of disability studies feminists Jenny Morris and Angharad Beckett, which critiques earlier theoretical frameworks for understanding citizenship and advances a human rights approach.

The final section, Governance and Independent Living, explores the governance structures that can or could facilitate the process of citizenship for disabled people. The interconnections with the social model of disability highlight the ways in which governance is viewed and theorised, and enables exploration of structure and agency level explanations of society. This includes an examination of the value of comparative governance analysis. This type of analysis has been utilised within disability studies, for instance, to develop theorising of disability and citizenship across different welfare regimes.

The origins of Centres for Inclusive Living (CILs) are then traced and the ways in which the Cooperative Movement has influenced their development and employment of user led governance are explored. These organisations form collectives of disabled people's expression of needs. The discussion considers meso level governance (user led disabled people's organisations) as a key facilitator for disabled people's access to independent living, and the questions that this raises in terms of the future of welfare resource and service distribution and operationalization.

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[1] If you have a right to do or to have something, you are morally or legally entitled to do it or to have it. (Collins English Dictionary, 2017)

The impact of CILs is explored through a focus on two specific areas of independent living, namely personal assistance and accessible housing. These are included within the 12 Pillars of Independent Living (Spectrum, 2016) and reflect the priorities defined by the research participants that took part in this doctoral study. The discussion considers the ways in which CILs have assisted with the progression of personal assistance and accessible housing services in Scotland and in Norway and prompted social policy changes, and explores the importance of informal governance networks created by CILs in operationalising independent living for disabled people.

This chapter closes with a summary of the main findings of the review which first highlights key empirical findings and then makes clear how this research draws on and expands current theorising around the notions of disability, citizenship and governance.

## 2.1 Disability and Independent Living

To understand and critically examine evidence on disabled people's access to independent living within Western Europe, the journey must begin with a historical perspective of disability. This section outlines key definitions of disability that have emerged across different periods of time, the factors that have influenced these formations and where potential contentions on reconstructing disability may arise in the future. It also highlights how definitions of disability can vary according to different perspectives, such as medical categorisations of disability and impairment, disabled people's subjective viewpoints and the terminologies used within legal and administrative frameworks (Grönvik, 2009). Additionally, this section examines key theoretical models that can be applied in the analysis of disability.

### 2.1.1 Definitions of Disability

Oliver and Barnes (1998) pointed out that definitions of disability have changed throughout history and, although some cultural variations exist, the treatment and regard of disabled people across countries over time holds a high degree of consistency. Thus, it is possible to unravel societal value systems, policy norms

and perceptions that have informed definitions of disability across different periods of time.

Thomas (2010) has noted that most theoretical perspectives within disability studies aim to contribute to the social emancipation of disabled people. However, there are two contrasting lines of thought in regard to the history of disability, namely the cultural turn[2] and materialism. In relation to the cultural turn, one of the founder theorists of post-modernism was Comte (1877), who developed what he termed 'social physics' between 1853 and 1871 (Thomas, 2010). He proposed a historical development of societies through the mode of consciousness or culture. This spanned three stages: theological (religious understanding of reality), the metaphysical (naturalistic understanding of reality) and the positivistic (scientific encompassing the social understanding of reality) (McClimens and Richardson, 2010). Post-modernist authors, such as Shakespeare (1996a) and Corker (1998) have attached importance to the cultural turn in social sciences. Historical changes have relied upon cultural, discursive and linguistic evolutions across time (Thomas, 2010).

Contrastingly, Finkelstein (1980) suggests a three-phase materialistic model in the development of attitudes towards disability. Table 2.1 shows the phases of Finkelstein's model laid out with a short description and the historical time-line of each. This model prioritises the economic organisation of society. In particular, the period of industrialisation, along with post-enlightenment thinking, served to culturally and spatially marginalise those deemed unfit members of the capitalist workforce and to perpetuate a normal versus deviancy divide between non-disabled and disabled people. Within disability studies, Finkelstein's writings have influenced authors such as Oliver (1990) and Barnes (1991).

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[2] The term 'cultural turn' means the acknowledgement by social sciences that epistemologically, (a) culture is viewed as universally constitutive of social relations and identities; and (b) supports the historical proposition that culture which is made up of social relations plays an important part in constituting identities in contemporary society (see, for example, Giddens 1984, 1991).

**Table 2.1 Three-phase Materialistic Model (Finkelstein, 1980)**

| Phase | Time Period | Description |
|-------|-------------|-------------|
| Phase 1 | 16th – 18th century | An agriculture-based society with inclusion of disabled people as part of a large subservient class. |
| Phase 2 | 18th – early 20th century | Industry-based societies where disabled people are segregated via institutions, such as special education or workhouses. |
| Phase 3 | 1945 – present | Modern service-sector dominated capitalism started in latter half of the 20th century with the removal of some social restrictions, technology advancements and partnership working between disabled people and professionals for better life opportunities. |

Source: Author

Despite the differences of theoretical opinion on the nature of change presented above, it is possible to trace the history of societal treatment of disabled people across different periods of time.

### *Disability and the Middle Ages*

In the UK, early categorisations of disability based on severity of physical and mental impairments can be traced back to seventeenth century Poor Laws. The passing of the Poor Law Amendment Act 1834 introduced a workhouse in each parish. These were administrated by parishioners and overseen by the Poor Law Commission.

The Poor Law Amendment Act 1834 also served to consolidate a three-pronged approach towards the treatment of disabled people. This involved institutions, such as workhouses, relief by charities and self-help (Symonds and Kelly, 1998). Stone (1985) outlined the way that eligibility criteria were implemented, which went on to form the basis of a definition of disability within these early welfare policies:

> *"In the regulations of the Poor Law administration and thus in the eyes of the Poor Law administrators, five categories were important in defining the internal universe of paupers; children, the sick, the insane, 'defectives', and the 'aged and infirm'. Of these, all but the first are part of today's concept of disability. The five groups were the means of defining who was able-bodied;*

*if a person didn't fall into one of them, he was able-bodied by default. This strategy of definition by default remains at the core of the current disability programs"* (Stone, 1985: p.40).

### *Industrialisation*

Scotland and Norway both experienced major industrial, cultural and political developments by the turn of the 20th century that paved the way for their modern welfare states (Barnes and Mercer, 1996; Cronin et al., 1998; Hanssen et al., 2001; Murphy, 1987). Oliver (1990) argued that these developments were mainly due to the change in nature of a person's contribution. Before industrialisation, disabled people could contribute more easily towards families or their communities since much production was small-scale, locally or home-based, and craft skills attracted a premium. However, industrialisation signalled the domination of capitalism with an individual's contribution tied to their productivity for profit.

Williams (1989) has noted that welfare policies at this time began to recognise:

> *"…the economic and social organisation of production - the needs of capitalism (for a literate, healthy and obedient workforce) on the one hand, and the struggles of the working class to improve their working and living conditions on the other"* (Williams, 1989: p.XIII).

As Ryan and Thomas (1987) discuss, industrialisation led to the intensification of efficiency within the work place. They comment that, *"The speed of factory work, the enforced discipline, the time keeping and production norms..."* (Ryan and Thomas, 1987: p.101) excluded many disabled individuals. The preceding agrarian economy had been slower and more flexible to allow for self-determination.

Clinical medicine became an essential intervention to segregate those deemed abnormal members of the workforce (Foucault, 1971 and 1976; Nettleton, 1995). This constructed the category of disability whereby on one hand societal beliefs supported that illness was not consciously controlled by an individual and on the other hand, validated the diagnosis of genuine and artificial forms of disability (Stone, 1985). Advancements in medical diagnosis provided a strategy of

determination that informed welfare decisions: should a case be institutionalised, receive aid or be refuted. As Stone summarised:

> *"Clinical medicine, then, offered a model of illness that gave legitimacy to claims for social aid, and it offered a method of validation that would render administration of the category feasible"* (Stone, 1985: p.91).

This rise by medicine to dominate societal perspectives occurred in parallel with the changes under industrialisation, for example, Malthus's Principle of Population written in 1798. The concept of normalcy developed further during the next century through the science of eugenics, a term introduced by Galton in 1892 to refer to selective breeding programmes designed to improve the quality of the human species (Kerr and Shakespeare, 2002). Empirical research was developed, and statistics were used to separate out disabled people from the general population. Eugenics can take 'strong' or 'weak' forms. The former refers to policies and practices that encourage reproduction of perceived good stock, whilst the latter refers to interventions such as sterilisation to prevent reproduction of those deemed unfit (Shakespeare, 1998).

The Eugenics Movement culminated in a voluntary approach towards the sterilisation of disabled people in the UK (Kerr and Shakespeare, 2002); whilst in contrast, Norway's policy response was compulsory sterilisation (Walmsley, 2000). In particular, high numbers of disabled women were subjected to these treatments. For example, figures from the 20th century showed that in Norway between 1934 and 1975, 48 000 disabled people were sterilised, while in the UK from April 1968-1969, 10 545 disabled women were sterilised during abortions, therefore preventing their future reproduction (Kerr and Shakespeare, 2002). Although it should be noted that the exact figures concerning compulsory sterilisation are contested (Drefvelin et al., 2003)

The period of industrialisation was also characterised by significant political changes.  In the UK, the latter half of the 1800s saw increasing support for 'new liberal' and socialist political ideologies which supported a collectivist approach towards welfare. However, the emphasis was particularly upon assistance for

disabled people who had acquired impairments whilst in employment that impacted negatively on their ability to work, which excluded much of the population. For example, the National Insurance Act 1911 gave provision for health care and unemployment tied to a contribution from a worker's wages, but excluded younger workers and women (Jones, 1999).

The UK Mental Deficiency Act 1913 has been viewed as a culmination of the industrial, political and social changes of the preceding century (Oliver and Barnes, 2012). It sought to categorise and segregate problematic societal groups, including disabled people, criminals and single-mothers. Disabled people were placed into four graded categories of idiot, imbecile, feeble minded and morally defective (Roulstone and Prideaux, 2012). As Williams (1989) remarked, this approach was adopted in relation to the ideologies of race, class and gender at the time. It served to segregate those deemed unfit from the wage market and unburden families of members viewed as dependent.

As with the Poor Laws in the UK, early legislation in Norway placed responsibility for welfare at a local level. In 1837, the Alderman Act laid down the rights and responsibilities of Norwegian municipalities (equivalent to local authorities in the UK) towards the welfare of their citizens. This was mainly due to health concerns of the Norwegian population, with a large gap between the rich and the poor, high infant mortality rates and an increase in diseases due to urbanisation under a shift to industrialisation (Nordhagen et al., 2014).

Similarly to the UK, early social policies that touched upon disability were focused on employment insurance. For example, in 1909 Norway brought in a compulsory sickness insurance system. Hanssen et al. (2001) explain that in Norway social security was first addressed at a national level during the 1920s with political parties differing in relation to their views on eligibility criteria and payments under social security programs.

### *The Modern Welfare State*

Informed by Keynesian economic principles of full employment, following the Second World War the UK and Norway both concluded that their welfare states needed to be transformed in order to meet the needs of their populations (Barnett, 2013). In the UK this influenced William Beveridge's blueprint for the 1945 modern welfare state. Beveridge distinguished five evils to be combated through welfare, namely squalor, idleness, ignorance, want and disease (Timmins, 2001). After 1945, Norway's Labour government introduced a raft of social policies aimed at the equalisation of people's life outcomes. This included the 1961 Disability Allowance and Rehabilitation Act.

Stone (1985) has discussed the significance of the latter half of the 20th century for the establishment of welfare states across Europe, including Scotland and Norway. Stone argues that there are commonalities in the ways that countries have entrenched the category of disability within their welfare systems that distinguishes between work and need-based distribution. Clinical diagnosis plays an important role in this process.

Stone (1985) highlighted the increase of disability benefit recipients across European countries during the 1960s and 1970s, which included both Scotland and Norway. This was attributed to ageing populations with higher rates of associated impairment levels, along with medical and technological advancements that enhanced overall life expectancy. She also noted that people had become more aware of their potential entitlements, as well as encountering less stigmatisation as a disabled person.

Although in the majority of countries disability welfare payments were low, they provided a stable income, particularly throughout periods of high unemployment that could be attractive to individuals with impairments.

The discussion above has briefly traced the changing historical definitions of disability and the ways that these have been tied to the development of welfare policies in Scotland and Norway. Within welfare systems, limited resources and a sense of moral obligation to contribute towards society (through paid labour) have

served to perpetuate the role of medicine to distinguish between genuine and fake cases of impairments in relation to specified eligibility criteria for state support or services (Oliver and Barnes, 2012). However, other forces have shaped current understandings of disability. During the latter half of the 20th century, disquiet arose among disabled people in relation to their treatment and objectification by societies. A collective identity was formed under the Independent Living Movement and this emerged to influence recent definitions of disability.

### 2.1.2 Independent Living and Social Policy

According to Davidson et al. (1999) a sense of difference between disabled people and non-disabled people has formed the foundations of welfare policies. This perception has in turn been perpetuated by the medical model of disability. Beckett (2006) states that this construction of welfare policies has two main consequences:

> *"Firstly, the development of a number of often disempowering apparatuses of welfare for disabled people, based upon assumptions about their special needs and their dependency. Secondly, it further supports the notion of bodily perfection, in which disabled people are viewed as the imperfect other and the non-disabled community refuse to accept their own, perhaps less visible, bodily imperfections or vulnerabilities"* (Beckett, 2006: p.175).

As Hunt (2001) noted, the latter half of the 20th century was characterised by an emergence of a collective awareness and collective identity among disabled people within institutional settings. Although this formed the basis of the Independent Living Movement, it is necessary to consider the act of independent living, since within the Independent Living Movement and wider debates in disability studies there are conflicting views on the operationalisation of independent living for disabled people.

Dr Radzka Adolf from the Independent Living Institute in Sweden has highlighted the various subjective meanings that the term independent living holds for different disabled people (Independent Living Institute, 2016). It can emphasise key points essential to a particular individual. These personal accounts illuminate common interests and common grounds for collective action: independent living is about

having the same choices, freedoms and rights as everybody else and support from social and financial societal structures. However, Wilkinson and Pickett (2009) acknowledge that general inequalities are largely determined by individuals' level of incomes and social class positions.

One of the earliest definitions of independent living, and one that still influences more recent definitions, is that derived by the Derbyshire Centre for Inclusive Living. In 1981 in collaboration with disabled people the Centre developed a list of seven needs of independent living including, but not exclusive to, personal assistance. Hampshire and Southampton (now known as Spectrum) CILs later developed the 12 Pillars of Independent Living, also referred to as The Basic Rights or 12 Pillars of Full Citizenship. This model was adopted in 2010 by CILs across the UK. The model expands upon the original seven needs of independent living as shown in Table 2.2.

### 2.1.3 The Operationalisation of Independent Living

The operationalisation of independent living has encountered a shift in campaign strategy from a National Disability Income in the 1960s towards rights-based anti-discrimination policies in the 1990s (Pearson and Trevisan, 2015). This has led to significant change in terms of legislation enacting policies to enhance disabled people's access to independent living. The effect of these legislative changes are still visible today. Table 2.3 presents an overview of the key policies within Scotland that have shaped the areas of equality, access to personal assistance and accessible housing. These policies operationalise the Scottish Government's perspective towards disabled peoples' rights to access independent living.

Table 2.4 meanwhile depicts the key policy developments in Norway in relation to disabled people's equality, personal assistance and accessible housing. These policy developments came to fruition through pressure from disabled people's campaign groups, such as Uloba (Norway's sole centre for independent living). Table 2.4 also illustrates Norwegian divergence from Scotland in relation to a rights-based policy approach towards disability. Norway exhibits a stronger regulatory approach at a macro (national) level in order to remove barriers that

hinder independent living for disabled people through measures, such as mandatory universal design (Hvinden and Halvorsen, 2003).

**Table 2.2 7 Needs of Independent Living Mapped against the 12 Pillars of Independent Living**

| 12 Pillars of Independent Living (Spectrum, 2016) | 7 Needs of Independent Living (Derbyshire CIL, 2016) |
|---|---|
| 1. Appropriate and accessible information | **Information** – to know what your options are |
| 2. Availability of peer counselling | **Peer Support** – encouragement and guidance from other disabled people |
| 3. Availability of accessible and adapted housing | **Housing** – a suitable place to live |
| 4. Adequate provision of technical aids and equipment | **Equipment** - technical aids, to reduce unnecessary dependence on others |
| 5. Adequate provision of personal assistance | **Personal Assistance** – human help with everyday tasks |
| 6. A fully-accessible transport system | **Transport** – to get where you need to be |
| 7. Full access to the environment | **Access to the Environment** – to go where everyone else does |
| 8. An adequate income | |
| 9. Availability of inclusive education and training | |
| 10. Equal opportunities for employment | |
| 11. Availability of independent advocacy and self-advocacy | |
| 12. Appropriate and accessible health and social care provisions | |

Source: Author

**Table 2.3 Policies for Personal Assistance and Accessible Housing in Scotland**

| Where Articulated | Year | Key Features for Disabled People |
|---|---|---|
| Section 12 of the Social Work (Scotland) Act | 1968 | Allowed cash payments to be made available by local authorities in exceptional circumstances. |
| Disability Discrimination Act | 1995 | Improved access to public and private service provision. |
| Community Care (Direct Payments) Act | 1996 | Introduced direct payments to disabled people to use in the delivery of their care. This moved away from local authority managed service-provision. |
| The Human Rights Act | 1998 | Based on the 1948 UN Universal Declaration of Human Rights goals for equal opportunities, full participation and respect for difference. |
| Part M of the Building Regulations | 1999 | Visit-ability standard with, for instance, level access to property, accessible circulation of ground floor. |
| Adults with Incapacity (Scotland) Act | 2000 | Provides framework for the protection of individuals over 16 years of age who are deemed to lack capacity to make life decisions. Welfare guardianships can be appointed to safe-guard their financial and social needs. The Act aims to increase their participation throughout the decision-making process. |
| Disability Discrimination Act | 2006 | Sets the scope and levels of mandatory grant for adaptions for people in the private sector, and puts a duty on local authorities to provide assistance, through the Scheme of Assistance, where adaptations are not covered by mandatory grant. |
| Changing Lives: Report of the 21st Century Social Work Review in Scotland | 2006 | Personalisation: build an individual's capacity to manage their own lives; individuals with complex cases to shape their solutions; and mechanism of consumer choice. |
| Equality Act | 2010 | Sets out reasonable adjustments, which must be made to prevent disabled people being at a substantial disadvantage in accessing services. However, the requirement does not include structural adaptations to the home. |
| Homes Fit for the 21st Century | 2011 | The Scottish Government's action plan for housing during the next decade. |
| Social Care (Self-directed Support) (Scotland) Act | 2013 | Amalgamated previous legislation on social care, stipulates self-directed options for disabled people and outlines local authorities' responsibilities to execute Self-directed Support. |
| The Scottish Housing Quality Standard | 2015 | Ensures water tightness and good repair of properties. |

Source: Author

**Table 2.4 Policies for Personal Assistance and Accessible Housing in Norway**

| Where Articulated | Year | Key Features for Disabled People |
|---|---|---|
| Local Government (Miscellaneous Provisions) Act | 1982 | Municipal responsibility for long-term care services. |
| Universal Design (devised by Weisman) | 1992 | Inclusive approach incorporating flexibility, accommodation of a person's life course needs and eradication of special social status or power relations. |
| Section 4-2 of the Social Services Act | 2000 | Legalised user-controlled personal assistance in Norway. |
| Social Service Act 4.2 and 8.4 | 2006 | Municipalities must offer user-control option for social care as part of its social care services. Extended user-control to disabled people unable to act as supervisors of their assistants. |
| Norwegian Anti-Discrimination and Accessibility Act | 2008 | 2025 accessibility across planning codes, new build housing, transport and IT systems. |
| Municipal Health and Social Care Act | 2011 | Although municipalities are obliged to secure quality services by law, they do not necessarily need to provide the services. |
| Section 3-8 of the Health and Social Care Act | 2011 | Obliging municipalities to offer support and training for user-controlled personal assistance. |

Source: Author

The Norwegian Anti-Discrimination and Accessibility Act (2008) demonstrated a move towards a rights-based approach to disability within social policy. This perspective developed not only from practical definitions of independent living such as those outlined above, but also from the philosophy of independent living. This ethos began in Berkeley, California, USA before spreading to Europe (Hunt, 2001). The linchpin for change was empowerment of disabled people. Instead of focusing upon the degree to which people can perform tasks, this concept emphasised autonomy over life choices (Shakespeare, 1996b), over institutional practices (Ramcharan et al., 2005) and over the ways in which personal choices are executed (Hillyer, 1993; Imrie, 2004).

Disabled residents of an institutional care home called Le Court formed the first collective resistance towards existing social policies and practices in the UK (Mason, 1990). During the 1950-60s they demanded representation on Le Court's board to combat restrictive procedures and their right to live independently within mainstream communities. For instance, they were not allowed to decide when they wanted to go to bed. In protest, many visited a local pub wearing their pyjamas. This struggle centred on autonomy, which Doyal and Gough defined as: *"to have the ability to make informed choices about what should be done and how to go about doing it"* (Doyal and Gough, 1991: p.53).

Thomas and Milligan (2015) note that disabled activists have been instrumental in putting forward the rights-based approach towards disability within social policy. This approach emphasises that people should have human rights in all areas of life. Post Second World War, the United Nations Universal Declaration of Human Rights (United Nations, 1948) was expanded to cover disabled individuals in 1985, which was influenced by the European Convention on Human Rights (ECHR) that came into force in 1953. In relation to disabled people's access to independent living, the following five articles from the ECHR are of particular importance:

- **Article 2** – the right to life (with virtually no exceptions)

- **Article 3** – prohibits inhuman or degrading treatment or punishment (with no exceptions or limitations)

- **Article 5** – everyone has the right to liberty and security of person (subject to lawful arrest or detention, which can include people with mental disorders)

- **Article 8** – the right to private and family life (subject to certain restrictions that are "in accordance with the law" and "necessary in a democratic society")

- **Article 14** – freedom from discrimination, including on the grounds of disability (but only in respect to the person's rights under the Convention).

The UK Human Rights Act 1998 sets out a framework for the implementation in policy and laws of the Universal Declaration of Human Rights (United Nations, 1948) and ECHR (1950). The Human Rights Act 1998 provides the power for cases put forward to a British court to be taken up by the European Court of Human Rights. At the time of writing, it should be noted that the UK Conservative government planned to repeal the Human Rights Act and replace it with a Bill of Rights (Full Fact, 2016).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international treaty adopted by the United Nations General Assembly in 2006. It was ratified by the UK on 8th June 2009 and by Norway on June 3rd, 2013 (United Nations, 2016). As well as providing a comprehensive legal framework for disabled people's human rights, it puts forward that disabled people are not different from the rest of society. However, Thomas and Milligan (2015) note that the UNCRPD uses a concept of disability to achieve this. It recognised that:

> *"Disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others"* (United Nations, 2007, n.p.).

The Office for Disability Issues (2011) produced the UK Initial Report on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which provides evidence on disabled people's access independent living in the UK. In particular, *Article 19 - Living independently and being included in the community*, highlights that the area of equalities is a reserved power, controlled by the Westminster Government. Examples of related legislation includes the Equality 2010 Act. However, the report also acknowledges that Scotland pursue their own agenda in terms of addressing compliance to the UNCRPD. The information specifically focussed upon Scotland sets out the Scottish Government's responsibilities in relation to devolved areas associated with independent living, including accessible/adapted housing and provisions for personal assistance services, and recognises that steps are required in order to protect the human

rights of disabled people. Since publication of the UK initial report on the UNCRPD, the Scottish Government has invited contributions from disabled people through a series of events organised by the Scottish Human Rights Commission (SHRC) and Equality and Human Rights Commission (EHRC). Additionally, many of the responses from individual disabled people's organisations can be viewed on the Independent Living in Scotland (ILIS) website (ILIS, 2018).

The Scottish Government's (2016) A Fairer Scotland for Disabled People - Our Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities sets out a strategy through which a co-production approach involving the Scottish Government, disabled people's organisations, private and third sector bodies, and disabled individuals create change and enhance disabled people's access to independent living. The Scottish Government's Delivery Plan to 2021 is shaped by the lived experiences of disabled people and the organisations that represent disabled people. A consultation on the draft plan was completed by January 2016. The consultation included evidence gathered from a Disabled People's Summit that took place on the UN's International Day of Disabled People 2015 (3 December). 150 disabled participants and their supporters focused upon the commitments outlined in the UNCRPD Draft Delivery Plan.

A Fairer Scotland for Disabled People (Scottish Government, 2016) sets out five long-term ambitions and over 90 actions that aim to address Scotland's compliance with the UNCRPD. The five ambitions are:

1. Support services that promote independent living, meet needs and work together to enable life of choices, opportunities and participation. Health and social care support services are designed to meet - and do meet - the individual needs and outcomes of disabled people.

2. Decent incomes and fairer working lives. Making sure disabled people can enjoy full participation with an adequate income to participate in learning, in education, voluntary work or paid employment and retirement.

3. Places that are accessible to everyone. Housing and transport and the wider environment are fully accessible to enable disabled people to participate as full and equal citizens.

4. Protected rights. The rights of disabled people are fully protected and they receive fair treatment from justice systems at all times.

5. Active participation. Disabled people can participate as active citizens in all aspects of daily and public life in Scotland.

<div align="right">(Scottish Government, 2016: p.10)</div>

### 2.1.4 Review of Disability Theory

Internationally, social policy developments such as the UNCRPD have started to shift away from an impairment-based definition of disability. As indicated, these changes have been influenced by disabled activists and academics (Oliver and Barnes, 2012). In the 1980s disablism was recognised as a form of social oppression (Abberley, 1987). According to Thomas:

> *"Disablism refers to the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as 'impaired' by those deemed 'normal'. Disablism is social relational in character and constitutes a form of social oppression ... In addition to being enacted in person-to-person interactions, disablism may manifest itself in institutionalised and other socio-structural forms"* (Thomas, 2010: p.37).

Following on from this recognition of oppression, disability studies emerged as an academic discipline to challenge disabled people's representation as a deviant group within society, exploring disabled people's identities and the role of impairment. Morris (1996) suggests that impairment can be discussed in three ways: there is the definition agreed by the Union of Physically Impaired Against

Discrimination (UPIAS),[3] a subjective interpretation[4] and the wider social context of discrimination and of social exclusion upon those deemed impaired.[5]

The key theoretical perspectives within disability studies include the social model (Oliver, 1990), the social relational model (Thomas, 1999), post-structural (Shakespeare, 1996a) and critical realism (Watson, 2002). This research adopts the social relational model (Thomas, 1999). Such an approach has been influential during what Simonsen (2005) refers to as 'the Nordic consensus' (Thomas, 2008; Tøssebro, 2004). Simonsen (2005) suggests that Scandinavian countries have witnessed more peaceful and less militant disability ideologies, such as the notion of normalisation. The application of concepts of citizenship, normalcy and democracy reveals the ways in which lines are drawn in terms of who is perceived as deserving and non-deserving of resources and support (Kirkebæk and Simonsen, 2001).

There has been a strong influence from continental European philosophical and critical theoretical contexts, as well as what is referred to as a skeleton history. Firstly, a social relational model of disability emerged from continental European philosophical and critical theoretical contexts, which authors such as Tøssebro (2004) have used effectively to demonstrate the need to openly address oppression within Norway's special education system. The work of Foucault (1976) was particularly influential within Norwegian disability analysis, for instance Grue's (2009) use of critical discourse analysis and in psychiatric studies by Kirkebæk and Markussen (1997). Secondly, the term skeleton history is used to refer to the knowledge gained through state funded research in response to accusations of abuse against disabled people (Ericsson and Simonsen, 2005). Often, such

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[3] Definition of impairment as agreed by the UPIAS: *"…impairment as lacking part or all of a limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities"* (Barnes, 1996: p.14).

[4] Subjective interpretation of impairment refers to an individual's identification that an impairment exists. For example, short-sightedness may not be considered an impairment if the use of glasses assists with the performance of necessary tasks.

[5] Impairments can be defined by the wider society. For example, entitlement to resources or services may be based upon measurements of impairment severity.

investigations stemmed from past sterilisation practices, for example, those traced by Haave (2000) and Pettersen (2005).

The social relational model of disability seeks to capture the interplay between structural and agency level explanations of disability. For example, mixed-methods disability research can have a greater impact where biographies reveal the history of life projects, while statistics can corroborate general trends or patterns (Shah and Priestley, 2011). In the UK, the social relational model of disability has been developed by Thomas (1999), who argues that social interactions constitute complex heterogeneities within everyday practices that are series of social relations, representative of interplays between biology, human feeling, personal experiences, sensory and sensuous bodies, societal structures, non-human technologies, artefacts and objects.

Therefore, an understanding of disability is polycontextual and through its application deepens our knowledge of the ways in which social ordering is, or can be disrupted and changed (Schillmeier, 2010; Thomas, 1999). Thomas defines disability as:

> *"A form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being"* (Thomas, 1999: p.60).

Shakespeare (2006b), writing from a post-structural perspective within disability studies, puts forward a similar viewpoint of disability to that of Thomas (1999). He perceives it as a holistic process that arises from an individual's intrinsic factors (such as nature or severity of impairment and personality) and contextual factors (such as the reactions of others and how enabling or disabling an environment is). The post-structural approach became popular during the 1990s and 2000s (Thomas, 2010). Shakespeare and others have drawn upon attitudinal, discourse, ideological and other representations of disabled people throughout their analyses.

The social relational model and post-structural theories share a focus upon the importance of identity and the ways that this affects, for example, disabled individuals at a macro, policy making level and micro, agency level. The work of

Foucault has provided a foundation for much of post-structural theorising. In particular, Foucault's concept of biopower focuses attention on the ways normalcy is inscribed on bodies, either through discipline or regulation (Foucault, 1978). However, despite common concerns around normalcy, Thomas (2007) states that the social relations model and post-structural perspectives have epistemological, political and moral divides.

In contrast to the post-structural perspective, Watson (2002) puts forward a critical realist analysis of disability. He argues that the post-structural approach lacks space for agency-level reflectivity (Giddens, 1991). For instance, discourse and linguistic norms are imposed upon individuals (Butler, 1993). However, Watson (2002) questions the notion of a collective identity among disabled people. He points out that disabled people do not hold common religious beliefs, political preferences or social class. Impairment does not equate with an individual's ontology, or sense of being, since impairment is a fact and not a product of discursive practices. In other words, identifiers such as age, ethnicity, relationship status or occupational role can dominate a person's sense of self.

The role of impairment in the construction of disabled people's identities is approached differently by Thomas. A key concept for Thomas (1999) is impairment effects. This denotes acknowledgement of the existence of an individual's impairments and the ways in which they impact upon lived experiences of disablement. Fatigue, for instance, is difficult to measure or quantify and may vary from day to day. These variations mean that for some people, the extent to which they can carry out everyday activities is determined on a daily basis. Connections with pain, suffering or premature death makes having an impairment an important differentiation from other groups within societies (Shakespeare, 1998).

French (1994) drew attention to the role that impairment plays within disabled people's debate on inclusion. She points out that measures to include one group of disabled people can serve to exclude another. For example, French (1994) argues that kerbs may be beneficial navigational markers for people with visual impairments but could be environmental obstructions for wheelchair users. Lord Lowe (2004) also asserted that, even with adjustments, the effects of an

individual's impairment will prevent a disabled person attaining a performance comparable to that of their non-disabled counterpart in some situations. He suggested, for example, that although visually impaired individuals can manage to navigate and make sense of online information at speed with the use of assistive technologies, their sighted colleagues can skim read and perform the same tasks faster.

The social relational model adopts a subjective definition of impairment. This has been supported by Grue's (2009) analysis of distinctions in Norwegian social policy between impaired and non-impaired persons in context of issues encountered by the Norwegian Anti-Discrimination and Accessibility Act 2008. The proposed legislation posed many questions. For example, at what moment is a body deemed impaired? How can subjective measurements of severity be made? Where is the line between short or long-term conditions? What is the role of impairment as an impediment? As Grue (2009) concludes, distinctions between impairment and non-impairment can be difficult to assess and can be subject to levels of individual subjectivity or health conditions that fluctuate. Shakespeare (2006: p.41) notes that:

> *"But even in the absence of social barriers or oppression, it would still be problematic to have an impairment because many impairments are limiting or difficult, not neutral."*

Disabled people may also encounter barriers to participation in society similar to those of other excluded groups, for example, low incomes. However, disabled people also encounter attitudinal and physical prejudice or obstructions which are unique (Hemingway, 2011). As Keith (1996) explains, at an agency level disabled people need to learn how to 'do disability'. Smiles, gestures, comments or questions from others can constantly impose discriminatory attitudes or negative images upon social interactions and, as Keith points out, deflection requires constant effort:

*"Doing disability all day long can be an exhausting process. I don't mean having an impairment, in my own case not being able to walk. Like most disabled people I can deal with this. I mean having to spend a significant part of each day dealing with a physical world which is historically designed to exclude me and, even more tiring, dealing with other people's preconceptions and misconceptions about me. If disabled people are to come out of these encounters confident and whole, we have to understand what is going on. We have to learn to channel these experiences, filter them and make sense of them holding on to our pride and our right to go about our daily business in our own independent and private way"* (Keith, 1996: p.71).

Grönvik's (2009) study examined existing definitions of disability and highlighted the need for researchers to be aware of methodological implications where, for instance, disciplines may hold different interpretations. The study drew upon secondary analysis of survey data in Sweden. It highlighted three main definitions of disability: firstly, functional definitions which stem from medical identification of body changes often, but not always, referred to as impairments; secondly, legal or administrative definitions of disability that originate from the distribution of welfare benefits to disabled people; and, thirdly, the subjective definition of disability where people voluntarily self-label as disabled.

Grönvik found an example of the interplay between the definition of disability and welfare in the over-representation of young, single males in functional and administrative definitions and a contrasting over-representation of females in subjective definitions. The explanation for this, according to Grönvik, lies with the functional and administrative definitions tied to a person's ability to participate in paid work and eligibility for welfare - a male dominated sphere of life. Furthermore, Grönvik continues, males are also more likely to demonstrate a reluctance to identify with a stigmatised minority group within society.

Grönvik (2009) points out that efforts have been made to address these definitional problems. For example, the World Health Organization asserted that the aim of the International Classification of Functioning, Disability and Health (ICF) was:

*"…to establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities"* (World Health Organization, 2001: p.5).

A notable omission from Grönvik's (2009) study was the social model of disability, devised by disabled activists and sociologists (Oliver, 1990; UPIAS, 1976). This emerged to challenge the medical model of disability that locates disability within an individual's impairment (Drake, 1999), and the associated segregative institutions, discretionary service delivery, in terms of the gatekeeper culture exercised by professionals who dominated service and resource provision, and the lack of enforcement surrounding the need for accessible public places (Barnes et al., 1999; Bull, 1998; Oliver and Barnes, 1998; Sapey et al., 1999).

Thomas (2008) is among those who highlight that the social model needs to go beyond a structural analysis of social oppression (Oliver, 2003) and include the theorising of impairment. The social model has been accused of being driven from a white, middle-class, male perspective, having ignored the fact that disabled women encountered greater disadvantage in comparable situations than their disabled male counterparts (Crow, 1992; Parker, 1993). Many authors have highlighted the need for research to prevent a wheelchair-user dominant perspective within disability and to incorporate the needs and views of people with sensory impairments (Corker, 1993 and 1998; Harris and Thornton, 2005) or cognitive impairments (Corbett, 1994; McNamara, 1996; Walmsley, 2000).

Shakespeare (2004) argues that a major factor for the social model's domination over other theorising of disability, such as the social relational model, in the UK has been its ability to connect with practice. As he explained, *"Political tools have to be understandable, memorable and relevant"* (Shakespeare, 2004: p.11). However, the social model has lacked empirical application in research (Shakespeare, 2004; Thomas and Milligan, 2015). Although it has led to recent policy changes, such as the UK Disability Discrimination Act in 1995 (Thomas, 2008), it remains a theoretical framework rather than an operationalised definition of disability (Shakespeare, 2006), lending support to Grönvik's (2009) conclusion that:

*"More research on the impact of disability definitions is needed before strategies for coping with this conceptual dilemma can be fruitfully discussed and remedies suggested"* (Grönvik, 2009: p.13).

### 2.1.5 Summary

The aim of this section was to outline the different definitions of disability, the historical to present day connections with welfare entitlements and the contribution of a social relational model of disability towards analysis. Industrial, political and cultural changes across Western European countries, particularly during the 19th and early 20th centuries, established and perpetuated an impairment-based category of disability, for instance, the UK Mental Deficiency Act 1913, which enacted policy that sought to identify, segregate and sterilise those deemed unable to participate in paid labour (Roulstone and Prideaux, 2012). Clinical medicine played a crucial diagnostic role to distinguish genuine and artificial cases of disability. As Oliver and Barnes (2012: p.41) have remarked, if it is viewed as an individual's pathological condition then:

*"…the medical community is not merely justified but obligated to prevent disability. In practice this means amending and rehabilitating people with impairments and even preventing the existence of such people. And because this kind of project would be morally sound, society ought to support medicine in its efforts."*

It was not until the latter half of the 20th century that a collective awareness among disabled activists led to the spread of the independent living philosophy from the USA to Europe. In practical terms, this concept denoted disabled people's rights to access all areas of life (see the 12 Pillars of Independent Living (Spectrum, 2016)). This collective action also increased recognition that independent living requires a holistic perspective (French and Swain, 2008) and, in philosophical terms, gave rise to the social model of disability (Oliver, 1990; UPIAS, 1976). Thomas (2008) acknowledges that the latter was radical for the time and assisted with policy changes such as the introduction in the UK of the Disability Discrimination Act 1995. However, a social barrier perspective fails to recognise:

1. that impairment plays a very significant role in most disabled people's lives, and;

2. that "disability" would remain if all social barriers were removed because impairment effects would continue to restrict some people's activity (Shakespeare, 2006).

Thomas (1999) put forward the social relational model, which seeks to combine structural and agency level explanations of lived experiences of disablement. This model has been particularly dominant in the Nordic countries (Simonsen, 2005; Tøssebro, 2004). Grönvik's (2009) analysis of definitions of disability within Sweden highlighted that researchers need to be alert to the multiple cross-disciplinary definitions of disability. However, Thomas and Milligan's (2015) recent publication demonstrates how the social relational model can support a rights-based approach for future improvements to disabled people's access to independent living. A strength of the social relational model is that it translates disability analysis, in terms of structural and agency level explanations, into operationalisation of independent living. In addition, it can offer a valuable insight, through an examination of impairment effects, which Thomas (1999) noted can impact upon situations even when all barriers have been removed and can form important elements of lived experiences of disablement.  In weighing up the strengths and weaknesses of each theoretical model of disability, this doctorial research adopts the social relational model as the central theoretical framework.

## 2.2 What is Citizenship?

This section presents Beckett's (2006) historical analysis of the concept of citizenship. Although Beckett published over ten years ago, her writing remains influential and outlines the interconnections between citizenship and independent living for disabled people. Beckett (2006) has remarked that theorising of citizenship can be difficult to undertake due to its entwined nature with other notions, such as democracy, liberty, justice, human rights discourses, the nature of the polis, the nature of the self, identity, difference, and struggle. In the UK, during the 1950s and 1960s, the writing of T. H. Marshall was prominent in the

sociology of citizenship. However, his ideas have been widely criticised, particularly from a feminist perspective (see Young and Quibell, 2000; Morris, 2005; Beckett, 2006), as discussed in greater detail below. Subsequent to T.H. Marshall's theorising, a neo-liberal framework from the 1980s came to dominate most European countries, and this section explores the implications this had for disabled people's access to full citizenship in Scotland and Norway. This literature review also traces the emergence of a social contract relationship between individuals and the state, and outlines the social liberal influence, especially during the formation of welfare. Furthermore, it will examine rights-based perspectives within disability studies. Jenny Morris and Angharad Beckett, in particular, put forward conceptualisations that have guided the analysis process throughout this research.

### 2.2.1 The Historical Emergence of Citizenship

Morris (2005) asserts that both political and academic perspectives on citizenship can be divided into two approaches, namely an individualistic approach and a structuralist approach. She outlined that:

> *"For the former, it is the individual's capacity to make choices that determines the nature of citizenship; for the latter individual action is much more influenced by social and economic factors"* (Morris, 2005: p.3).

Pattie et al. (2004), for example, highlight the perspective of citizenship where an unadulterated choice-based system is adopted that adheres to an economic premise. At an individualistic level, individuals strive to maximise their life chances and opportunities from any course of action, at the minimum cost. Contrastingly, the structuralist approach emphasises the role of social norms and values, with individual behaviour shaped by social and economic forces. For example, Oliver (1990) highlights that disabled people tend to encounter structural financial, political, environmental, attitudinal and communicational barriers to their full participation in society.

Beckett (2006) provides a detailed historical analysis of the evolution of the concept of citizenship and the interconnections with independent living for disabled people. Beckett (2006) noted that the earliest notion of citizenship appeared in the 16th

century through the first social contractual relationship between individuals and the state. At this time, citizens accepted sovereign rule in turn for benefits including physical protection. This social contract evoked individuals' legal and moral obligations towards the state and society. Beckett argued that the theoretical developments at this time in relation to citizenship provide the foundations for current debate and conceptualisations. For instance, the authoritarian perspectives of Hobbes and Locke, as well as the libertarian perspective of Rousseau, provide explanations behind the maintenance of this social contract. In Leviathan, Hobbes (1973) argues that people needed to choose between anarchy and absolutism. Essentially, Hobbes viewed people as self-interested and that any authority was preferable to natural chaos. However, it must be noted that his writings were coloured by the English Civil War (Beckett, 2006).

Beckett points out Clarke (1996) criticises Hobbes's perspective as a thin view of citizenship; the state keeps social order and subjects have few rights but are able to live in a socially ordered society. However, Faulks (2000) identified key areas where Hobbes had influenced later theorists:

- An individual is seen to be in a direct relationship with the state;

- Citizenship has links to equalities where individual action can upset the basis of social order;

- The state and the sovereign are visible;

- The concentration of power in the monarch will concentrate the means of violence.

Moreover, Beckett (2006) explained that Locke (1965) conceptualised an additional Contract of Trust. This set out an understanding between the society and its government that the government was authorised to protect the natural rights of its citizens. Thus, for the first time, there arose a reciprocal contract between the governing power and those governed. Rousseau (1913), on the other hand, proposed liberal republicanism, which offered a more optimistic explanation of the social contract that contributed towards the development of the notion of active

citizenship.[6] The common interests of society, known as the general will, took precedence over individualistic desires. Rousseau voiced mistrust in the ability of individuals to democratically follow a path that would be of benefit to all. However, he received criticism that he favoured the rights of the community over the individual, and this gave, what Beckett (2006) terms, 'a pessimistic end' to his theorising of citizenship.

### *Social Liberalism Perspective*

For UK social policy developments during the latter half of the 20th century, one of the most influential schools of thought has been social liberalism, as put forward by T. H. Marshall in 1949 (Marshall, 1952). Turner (1986) points out that Marshall's theorising of citizenship fits best with a social democratic perspective. Marshall (1963) presents the notion of educational meritocracy[6] with an emphasis upon equal opportunities and universal rights. What marked his departure from previous liberalists was a desire to eradicate poverty through the mitigation of the capitalist market that was failing to meet the needs of all people within society. However, Beckett (2006) disputes Marshall's liberal democratic credentials. As Beckett puts forward:

> *"He was not about social reform in a Marxist respect. Marshall's intention was only to moderate the worst excesses of capitalism through the promotion of the idea of citizenship and in so doing only to modify, rather than remove, the social class system"* (Beckett, 2006: p.38).

Therefore, an egalitarian social reform was less of an imperative for Marshall since he viewed equal citizenship as a compensation for any social inequalities (Mead, 1997).

In his 1952 paper, Citizenship and Social Class, Marshall identified three key components of citizenship, namely, civil, political and social rights. Firstly, civil rights denote individual freedoms regulated through, for example, law and civil rights to own property, exchange goods, services or labour. Secondly, political

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[6] Liberal republicanism describes the governance of a country through popular power (elected citizens). It is opposed to monarchical or dictatorship rule.

power can be exerted by voting. Thirdly, social rights highlight access to an appropriate standard of living, such as access to good quality healthcare (Bellamy, 2008; Morris, 2005).

Oliver and Heater (1994) questioned to what extent social rights can be achieved. They argue that conflict can arise with civil and political rights. They refer to the latter as first generation rights with a residual nature. Oliver and Heater (1994) assert that political rights serve the interests of an underlying capitalist value system. On the other hand, social rights are viewed as second generation rights, whereby there is an element of political will at play in order to secure the necessary financial resources. Barbalet (1988) expresses a similar opinion, highlighting the conditional nature of social rights and questioning whether these rights can truly be held as citizenship rights. Additionally, Delanty (2000) challenges five specific aspects of Marshall's theory of citizenship:

- Cultural rights are negated from social rights;

- Globalization and multiple modernities highlight divergence in citizenship development;

- An omission of the notion of participation;

- Citizenship depends upon a link between state and nation; and

- An assumed split between public and private spheres of life.

However, Beckett (2006) notes that it is important to acknowledge that Marshall tried to address these criticisms in 1981, twenty years after writing Citizenship and Social Class. In a lecture on power and rights, he focused upon the notions of social and political rights, specifically those that would prevent the domination of authoritarianism:

> *"[Marshall] stated that political rights can be easily undermined, and that social rights have not been designed for the exercise of power at all, but instead reflect the strong individualist element in society in which individuals are best viewed as consumers and not as actors. It is only civil rights that, according to Marshall, truly relate to the individual as actor"* (Beckett, 2006: p.43).

Marshall deliberates upon the use of power within the definition of citizenship. He asserts that this has equal importance to the attainment of power. Drawing upon the example of the Civil Rights Movement in the USA, Marshall highlights that the leaders did not call for redistributive power, but for a share in the total power of society. According to Marshall (1981: p.150):

> *"The goal is a new kind of society, truly multiracial or, should that prove impossible, then, some would say, composed of independent and equal racial communities."*

Beckett (2006) acknowledges that Marshall touches on the debate of multi-culturalism and the politics of difference (see the work of Kymlicka (1995) and Young (1990)). However, Beckett (2006) also provides a criticism of Marshall's approach towards the concept of citizenship. Firstly, she proposes that Marshall's concept of social rights provides a 'woolly' economic basis for social security. However, in 1973 Marshall did point out that there should be a distinction between absolute poverty[7] and social inequality. Within this, Beckett stated that Marshall's later additions did not acknowledge the power differences that can affect individual life chances. These potential interpersonal power differences can challenge Marshall's notion of meritocracy.

An example of the impact that power has upon civil rights can be found in the area of employment. Marshall based his assumptions of full employment in relation to the nuclear family structure; a male bread-winner participates in the production of labour while the female home-maker was responsible for the reproduction of the

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[7] In 1995 the United Nations defined absolute poverty as severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information. It depends not only on income but also on access to services. For an introduction to discussion on poverty overall, see Alcock et al. (2012).

future workforce (Parsons, 1959). This negates the often unpaid domestic and care responsibilities that predominately women undertook (Lister, 2003) and demonstrates gender assumptions inherent within the definitions of citizenship.

### Neo-Liberalism Perspective

The definition of citizenship has been affected by a neo-liberal distributive framework of welfare resource allocations which have emerged across most Western countries since the 1980s (Edgar et al., 2002; Gilbert et al., 2005). Christensen and Pilling's (2014) comparative analysis of personal assistance for disabled people in England and Norway highlights the challenges posed by a neo-liberal service delivery framework. They note that New Public Management (NPM) swept across Europe during the 1990s in response to democratic changes that include an acceptance of care as a public responsibility. It also sought to address the issues faced by ageing populations that bring with them higher rates of individuals with associated impairments and an increase in health related public expenditure.  A shared objective for European countries was to ascertain effective strategies to reduce the financial costs of social care.

Stewart and Walsh (1992) described that NPM involves the uncoupling of the purchaser from the provider role of services, an emphasis upon contractual or semi-contractual arrangements, construction of a market or quasi-market, the need for performance assessment and an ideology of public citizens as customers that are presented with choice. The notion of individual freedom, as explained, was expressed via different routes throughout both the democratic discourse (characterised by citizenship rights to be satisfied by the state, established in countries such as Norway), and the market discourse (customers exert rights through choice that can be found in the UK).

A Norwegian study conducted by Sandvin (2003) illustrates the effects of this welfare shift to a neo-liberalism framework upon disability. He utilised data from seventy in-depth life histories of people with a range of impairments spanning three generational cohorts. The central aim was to report upon the impact of social change and evaluated the impact of welfare state on the life conditions and

opportunities for disabled people during the second half of the 20th century in Norway.

Those representing the oldest generation were participants born in the 1930s who had been children during the war and entered adulthood in the very early phases of the modern welfare state; the middle generation were born in the 1950s and had grown up in a period characterised by social and economic safety; whilst the youngest cohort had been born in the 1970s, and therefore, encountered greater educational or life time choices than their predecessors. The starkest finding was illustrated via the youngest generation. They adhered to a life project, personal interests and their expression of identity revealed segregation or difference. Sandvin (2003) explains that this meant that blame or frustration surrounding choice was internalised (shifted inwards towards the self) whereas the other two generations directed frustrations externally (outwardly to society at large). The youngest generation also exhibited less of a collective identity through their impairment, although they remained aware of their rights or the potential forms of discrimination.

Authors such as Russell (1998), Young and Quibell (2000) and Morris (2005) contend that a neo-liberal regime makes full citizenship unattainable for disabled people. A climate of self-reliance, based upon mixed market economies, creates rather than dispels exclusion and perpetuates competition, especially amongst impairment-specific organisations, for scarce resources (Clare and Cox, 2003; Solvang et al., 2003). Ellis (2007) has also pointed out the dominant nature of a professional gate-keeper prerogative. Ellis asserts that policies are often manifested through discretionary powers wielded by, for instance, social workers In relation to direct payment decisions. However, front-line operationalisation and interpretations of policies or procedures can often fail to meet the needs of disabled people in practice (Disability Rights Task Force, 1999; Gilbert et al., 2005; Imrie, 1996; Kielland, 2010).

Therefore, under a neo-liberal framework, citizenship status can affect people's entitlement to resources or support. A study conducted by van Oorschot (2006), for example, examines the popular cultural contexts of welfare rationing and

variations of conditionality (co-variants at the aggregate and individual level) displayed by European public perceptions towards relative deservingness of different groups in need: the elderly, disabled, unemployed and immigrants. Data was collated from the 1999/2000 European Values Study survey of twenty-three countries. The findings show that informal solidarity was highest towards elderly people, followed by disabled people, then unemployed people. Solidarity towards immigrants was lowest. The study speculates that in countries with low social protection, such as Central and Eastern European countries, people would differentiate along the deservingness criterion of identity in terms of 'us' versus 'them'; whilst in affluent nations, such as the Scandinavian countries, differentiation would occur along the lines of incapacity, that is, the deservingness criterion of control.

However, a shared pattern across all twenty-three countries indicates that the underlying logic of deservingness has deep roots in popular welfare culture. Van Oorschot (2006: p.38) suggests that this was based upon the functionality survival of social groups:

> *"The deservingness criterion of identity protects the group against burdensome support claims from outside the group, while the criterion of control protects against such claims from inside the group."*

Also, there were not any disparities according to an individual's sex, age, educational level and income level, social position or religious denomination. A common theme was the rhetoric of responsible individual citizens; people are expected to be active in providing for themselves. Therefore, those in need and who do not conform can be blamed for their neediness. The study concludes that further multi-aggregate analysis was required to confirm these findings and investigate whether they are also apparent within non-European countries.

### 2.2.2 Rights-Based Perspectives and Disabled People's Citizenship

As noted earlier in the chapter, disabled activists and academics formed the Independent Living Movement during the second half of the 20th century (Oliver, 1990; UPIAS, 1976). The Independent Living Movement sought to improve

disabled people's access to all areas of life, inclusion and participation within society. Writers emerged within disability studies that supported a rights-based perspective, such as Zola (1989), who argued that disability should be perceived as part of a human identity and not the experience of a minority group. He proposes that societies should replace special needs labels with a life course perspective whereby dependency can occur at any point throughout a life time.  As Zola points out, nobody escapes ageing and everybody is susceptible to injury, disease and, inevitably, death.  He refers to this as the continuum of embodiment.

These sentiments were later picked up by the work of Morris (1992) who applied a feminist perspective towards analysis within disability studies. She illustrates the interconnections of gender and disability and tackles the dominance within early disability studies of a hegemonic male, middle-class, white, wheelchair-user perspective. She also uncovers the lived experiences of disablement, whereby disabled women's basic human rights were denied in practice (United Nations, 1948). For example, at the time of her writing many physically impaired women experienced prejudice relating to their choice to enter motherhood, often resulting in the immediate removal of their new born babies by police and social workers.

Morris (2001) pointed out that the United Nations Universal Declaration of Human Rights (United Nations, 1948) was introduced to prevent a state from designating specific groups as sub-human. A human rights perspective regards that everybody has the right to live, eat adequately, be housed, access clean water, experience health and hygiene, access privacy, education, work, marriage, reproduce, have freedom of expression, sexuality, share fully in the social life of their community and contribute to the wellbeing of others to the full extent of the individual's capabilities.

Morris (2005) points out that there are three main concepts that need to be operationalised in the future to facilitate disabled people's access to independent living, namely:

1. **Self-determination:** This has been an important concept for both the independent living and self-advocacy movements.

2. **Participation:** This concept is often used by disabled people when engaging with the debate on social exclusion. In terms of wider citizenship debates, the concept includes the civic republican concept of political participation, but also encompasses the broader concept of community participation.

3. **Contribution:** Disabled people have emphasised the value of their contribution to economic and social life when they make the case for both anti-discrimination legislation and the resources required for a reasonable quality of life.

(Adapted from Morris, 2005)

Turning to self-determination, Morris (2005) discusses that this notion echoes debates surrounding autonomy, consumerism and choice (see also Ruth Lister, 2007). Doyal and Gough define autonomy as:

*"To have the ability to make informed choices about what should be done and how to go about doing it"* (Doyal and Gough, 1991: p.53).

Morris highlights that people with cognitive impairments may require support in order to understand and choose between different options, for example, in their care delivery. However, the state expects such support to largely fall to the voluntary sector, where the majority of these organisations adopt a medicalised perspective of disabled people as a passive and dependent group.

According to Morris (2005), the main barriers to the participation of disabled people include unequal access to health care, attitudinal prejudice and physical and verbal social exclusion. In order to gain full participation, Morris (2005) argues that disabled people need social capital. She explains that the UK government formally adopted the OECD definition of social capital as:

> *"…networks together with shared norms, values and understandings that facilitate co-operation within or among groups"* (Cote and Healy, 2001: p.41).

Ahmad (2008) concurred that, particularly for minority groups within societies, social capital is an essential ingredient for effective civic engagement. This process can assist in building self-confidence and collective confidence. Self-management of social problems or social services has been a popular objective under the dispersal of decision-making powers from central governments (Wallace, 2009). However, participation can contain challenges, especially if individuals do not want to become involved or do not understand how to become involved. As Wallace (2009) concluded, self-management entails complexities yet to be fully examined and catered for by governance structures**.**

However, research has demonstrated that social capital can be difficult to attain for disabled people with limited life opportunities. For instance, Stehlik's (2004) article highlights preliminary findings from two studies looking at the experiences and social networks of disabled people and their families in communities in regional and rural Australia. It highlights the way that social capital is not simply a feature that can be switched on and off; it requires to be nurtured, with sustainability as a prerequisite for all forms of social capital. Different impairment types were found to reduce network building opportunities, with communities often excluding disabled people and their families, sometimes with the use of violence. Bonding social capital was apparent amongst participants who received peer support from similar families, volunteered within disability organisations or particularly, in the case of parents, took on advocacy roles.

The concept of citizenship has been bound up with an individual's responsibility to contribute through paid employment (Timmins, 2001). For Morris (2005), this raises questions around the notion of what constitutes a good citizen. For example, this can be other forms of contributory behaviour to society, such as voluntary work. Therefore, a disabled person who may utilise the flexibility provided by voluntary work and who relies upon welfare benefits, poses questions around whether they would be viewed as a full citizen.

Morris (2005) has pointed out the dependent relationship portrayed between social rights and citizenship rights. She discusses the example of community care legislation where under the 1990s delivery of community care, somebody who qualifies for support is not expected to fulfil citizenship responsibilities. Morris (2005) discusses the UK Government report, Improving the Life Chances of Disabled People (Prime Minister's Strategy Unit, 2005) which specifies some changes in relation to disabled people's access to independent living. Morris (2005) asserts that if the agenda was fully implemented, this would go a long way towards enhancing disabled people's access to independent living in the UK. The report proposes that each local authority area should have disabled people's organisations or Centre for Independent Living in order to provide localised support for disabled people to exert autonomy over their life choices and fully contribute towards society. However, Morris is critical of the report's scope. She identifies the following gaps or weaknesses that need to be addressed in order to fully enhance disabled people's access to independent living:

- There is no firm commitment to giving people an entitlement not to have to move into residential care in order to get the support they need;
- There is no firm commitment to redistribute and use resources in ways which enable disabled people to be fully included in society;
- There are no proposals to address the high risk of poverty experienced by disabled people or, in particular, the failure of disability benefit levels to meet the additional costs of impairment or illness;
- Its proposals are made in the context of continuing stigmatisation of people receiving incapacity benefit while at the same time there are significant cutbacks in the DWP making it difficult to deliver the personalised support the report identifies is needed to help people into work;
- The report does not cover people over retirement age.

(Morris, 2005: p.37)

For Morris though, the British Council of Organisations of Disabled People (now the British Council of Disabled People) produced the fundamental principles that should construct the citizenship of disabled people. They assert:

- all human life is of value;

- anyone, whatever their impairment, is capable of exerting choices;

- people who are disabled by society's reaction to physical, intellectual and sensory impairments and to emotional distress have the right to assert control over their lives;

- disabled people have the right to participate fully in society.

(Adapted from Morris, 1993)

These can be viewed as overarching rights that guide disabled people's access to all 12 Pillars of Independent Living (Spectrum, 2016). In a similar vein, Beckett's (2006) theorising on disability and citizenship has also attempted to put forward proposed changes to societal value systems in order to operationalise a rights-based approach. She has concentrated upon the concept of vulnerability. This has, along with disability, received negative connotations perpetuated by the media and popular beliefs.

However, Beckett draws upon the work of Turner (1992 and 1993), who developed the sociology of the body and citizenship. His theory of an embodied understanding of citizenship is based on a concept of personhood. This denoted, as expressed by Beckett (2006: p.64), that: *"...each person is both seen as, and is aware of, their own vulnerabilities"*. Thus, personhood is viewed as fragile and contingent; in other words, everybody is vulnerable in some way and at some point in their lives. These beliefs rest upon the following five considerations:

1. An elaborate understanding of the basic notion of embodiment, which would be a method of systematically exploring the complexity of the body in terms of its corporality, sensibility, and objectivity;

2. An embodied notion of social agency in the theory of social action and a comprehensive view of how body-image functions in social space;

3. A genuinely sociological appreciation of the reciprocity of social bodies over time, that is, an understanding of the collective nature of embodiment;

4. A historical sense of the body and its cultural formation;

5. A political understanding of the body in relation to governance, with special reference to what we might term corporeal citizenship, namely sexual regulation and surveillance of bodies by state legislation on reproductive technology, abortion, adoption, and parenting.

(Beckett, 2006: p.63)

One of the main goals of Beckett's (2006) writing was to introduce a process that amalgamates the theorising on citizenship, social movements and vulnerability. Beckett asserts that the arguments put forward should be seen as tentative and that a great deal more empirical research and associated theorising is required in order to comprehend the whole picture. This draws upon findings of a UK Economic and Social Research Council (ESRC) funded study carried out in 2000-2001 that involved six UK disability organisations, run by disabled people for disabled people. The research particularly sought to inject the voices of disabled people into citizenship and social movement theorising.

It is evident that Beckett's work expands upon that of Morris (2005). The concept of human rights is placed at the heart of citizenship where upon, Beckett outlined, the process of citizenship acts as an umbrella for human rights rather than the other way around. She used Isaiah Berlin's (1958) term of the minimal moral horizon to describe the overall objectives of human rights. Rights, responsibilities and obligations are then perceived as equal strands that make up the process of citizenship. For instance, if personhood encapsulates a sense of contingent vulnerability, then the act of an individual claiming their rights to protection from the effects of potential vulnerabilities would be acknowledging the rights of others to gain support for their actual vulnerabilities.

In doing so, it deconstructs the notion of otherness (Douglas, 1966) and social differentiations such as disability, racism, sexism, poverty or other forms of social

exclusion. It also eradicates the tension between structural and identity rights. Beckett argued that dominant groups within society would recognise and protect the vulnerability and specificity of cultural identities attached to individual's notions of personhood. However, a government that recognises vulnerabilities among society will need to increase resources to address these vulnerabilities.

In practical terms this would involve a high taxation approach. However, Beckett points out that such a move currently encounters resistance within the UK. Therefore, grass-root organisations and the educational system play an important role in that they need to foster the recognition of vulnerabilities and that anybody can become disabled. In time, this may grow an acceptance of an active citizenship process.

### 2.2.3 Summary

This section has highlighted that the concept of citizenship can be contested and is contentious. Beckett's (2006) historical analysis has provided insight into the emergence of citizenship during the 1600s when a social contract was constructed between individuals and the state. Beckett highlights the key theorists who offered different approaches to citizenship and developed the social liberal perspective that encompasses many different strands of thought.  For the UK, Marshall (1952) has been the most influential upon the development of social policy during the latter half of the 20th century.

However, authors such as Oliver and Heater (1994) and Delanty (2000) have pointed out that the attitudinal assumptions present in the 1950s have coloured Marshall's theorizing on citizenship. For instance, disabled people were omitted from Marshall's writing. Since the 1980s, a neo-liberal approach has come to dominate many European countries, including Scotland and Norway (Edgar et al., 2002; Gilbert et al., 2005). This has posed many challenges for disabled people and has created a climate where attainment of full citizenship has been deemed impossible (Russell, 1998). Thus, the rights-based perspectives towards citizenship arose from the Independent Living Movement. Morris' (2005) human rights approach is complemented by Beckett's (2006) theorising on the vulnerability

of personhood. In this way, each member of society becomes aware of their self-vulnerability and that of others, and supports a comprehensive resource distribution scheme to facilitate access to independent living for all.

## 2.3 Governance and Independent Living

As outlined in the first section of this chapter, Disability and Independent Living, the social relational model of disability (Thomas, 1999) calls for an analysis of structural and agency level explanations to understand disablement. This section applies this social relational framework to the concept of governance. Governance is a useful mechanism to examine the policies and practices that facilitate or impede disabled people's access to independent living at macro, meso and micro tiers of societies.

Richards and Smith (2002) outline that the notion of governance is open to interpretation. Broadly speaking, it refers to:

> *"…all processes of governing, whether undertaken by a government, market, or network, whether over a family, tribe, formal or informal organisation, or territory, and whether through laws, norms, power or language. Governance differs from government in that it focuses less on the state and its institutions and more on social practices and activities"* (Bevir, 2012: p.1).

Firstly, the independent living ethos is explored at a macro, structural and national level. This centres on national policies and decision-making frameworks from Scotland and Norway. Part of this journey involves the examination of theoretical postulations put forward by comparative research to enable learning around citizen outcomes across different cultural and economic contexts.

Secondly, this section explores the ways that the ethos of independent living has been embodied by meso, organisational governance. User led disabled people's organisations, for example, arose from early collective efforts of the Independent Living Movement. An examination of their historical development within Europe

show the ways they have challenged and still challenge nondisabled organisations that predominantly ascribed or ascribe to the medical model of disability.

Thirdly, micro agency level governance highlights disabled individual's engagement with elements of independent living. It outlines that of the 12 Pillars of Independent Living (Spectrum, 2016), certain aspects such as personal assistance have received a lot of attention. Contrastingly, other components, such as accessible housing, have attracted less coordinated engagement for change.

### 2.3.1 Macro Level Governance

The term macro governance in this literature review refers to national level policy and decision-making within Scotland and Norway. Wallace (2009) has noted that governance is a useful concept through which to explore the organisation and delivery of welfare resources. This can take formal and informal forms that are operationalised through state assumptions around civic engagement and expectations for the self-governance of citizens. Consequently, access to resources is controlled via regulatory and distributive policies (Hvinden and Halvorsen, 2003).

A focus upon welfare regime types across countries can, according to disability studies, utilise a comparative research perspective to gauge the progress towards independent living for disabled people across different societies. Such an approach has roots with the early inception of the Independent Living Movement in Berkley, America, and through knowledge transfer, spread across Europe (Zukas, 1975).

Simonsen (2005), writing within disability studies, also asserted that comparative research provides emphasis to the history of disability, furthers our understandings and can promote theory-generating around mechanisms for social inclusion. Cross-national comparative research can resemble the closest approximation to the controlled laboratory experiment for social scientists; it gives an opportunity to examine outcomes and note similarities or dissimilarities (Antal et al., 1987).

A theoretical framework that is widely used to compare and analyse national welfare states is Esping-Andersen's (1990) welfare state typologies. He identifies

three models of welfare states, as presented in Table 2.5. Such a comparative tool helps to highlight contextual divergences, with the aim of neither reduction nor generalisation, but in order to discern systemic patterns (Kemeny and Lowe, 1998; Preus, 1987).

Esping-Andersen rejected views that welfare states emerged as a natural outcome of policy development or due to the growth of democracy. Instead, he argues that they form due to philosophical forces, technological determinism or as a consequence of industrialisation (van Kempen and Murie, 2009). To assess a country's welfare regime typology, Esping-Andersen used seven indicators. These range from public expenditures for government employee pensions to private sector pensions, as well as the examination of decommodification levels and social stratification.[8]

It should be noted that critics of Esping-Andersen's analytical framework, such as Leibfried (1992) and Hoekstra (2003), have proposed alternative theorising of welfare regimes. Leibfried (1992) distinguishes four social policy or poverty regimes within European Community countries: the Scandinavian welfare states, the Bismarck countries, the Anglo-Saxon countries and the Latin Rim countries. These policy regimes are based on different policy models - modern, institutional, residual and rudimentary - in which social citizenship has developed in different and sometimes incomplete ways. Additionally, Hoekstra (2003) proposed that the hybrid nature of the Netherlands should be referred to as modern corporatism since, contrary to conservative values, localised power increased during the 1990s. There are challenges with finding pure types as well as the glaring omission of acknowledging partial citizenship experienced by women due to gendered inequalities, which ignores their contributions to welfare or care (Bulmer and Rees, 1996; Sainsbury, 1996; Siaroff, 1994). However, studies such as Schütz et al. (1998) highlight that Esping-Andersen's typologies are still relevant and provide useful value for comparative analyses.

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[8] The degree of de-commodification, i.e. the degree to which a (social) service is rendered as a matter of right, and the degree to which a person can maintain a livelihood without reliance on the market; and the kind of social stratification and solidarities, i.e. which social stratification system is promoted by social policy and whether the welfare state builds narrow or broad solidarities (Esping-Andersen, 1990).

**Table 2.5 Welfare Typologies Key Characteristics**

| Welfare Topology | Characteristics | Country |
|---|---|---|
| Liberal | Major programs are means-tested and stigmatised; modest social insurance, strict entitlement rules; widespread poverty and minimal de-commodification effect. | Scotland |
| Corporative | Less empathy on free market efficiency and commodification; rights attached to status and class; redistribution of strong historical link with church; welfare towards preserving traditional values of the family. | Netherlands |
| Social-democrat | Universal programs; de-commodification effect; social policies geared towards social equality; strong solidarity and loyalty to state. | Norway |

Source: (Author, after Esping-Andersen, 1990)

Turning to Scotland, which exhibits traits of a liberal regime type as defined by Esping-Andersen (1990). Authors such as Anderson and Sim (2011) and Nixon et al. (2010) point out that Scotland exhibited universalistic tendencies during the period of welfare expansion from 1945 to the mid-1970s. However, policy developments at a UK level impacted upon the governance structures and goals within Scotland. In 1999, Scotland became a devolved jurisdiction. Before and during this doctoral fieldwork in 2012, the policy areas of housing, health, education and public transport remained devolved powers from the Westminster government, while social security, EU membership and the military remain reserved matters.

Mooney and Scott (2012) point out that the policy-making process in Scotland differs compared to the rest of the UK due to proportional elections and a tendency towards coalition governments. The current Scottish National Party (SNP) majority government, elected in 2016, pursues an agenda with separatist issues from UK neighbours and supports a social democratic perspective (Mooney and Scott, 2012). The SNP has in some areas tried to mitigate specific policies or has declined to adopt some UK policy measures. For instance, the increase in rental contributions for households deemed under occupied within the social renting

sector under the UK Spare Room Subsidy policy[9] (2014) was off-set by the implementation of discretionary payments in Scotland (Department for Work and Pensions, 2014).

Since this study's fieldwork in 2012, Scotland held a referendum on independence in 2014. The pre-referendum campaign in 2014 saw Scottish ministers support a Nordic and Baltic policy statement designed to stimulate future collaborations, partnership working and joint research across Scotland, Iceland, Sweden, Norway, Denmark, Finland, Latvia, Lithuania and Estonia (Scottish Government, 2014). For instance, Nordic Horizons is an informal network of Scottish professionals (Nordic Horizons, 2015), such as Lesley Riddoch, who highlights Scotland's similarities to all the Nordic countries.

In relation to Norway specifically, Lesley Riddoch has pointed out potential Norwegian economic features that may be possible to replicate in Scotland (Riddoch, 2017). She highlights that as with Norway, Scotland's infrastructure could develop economic maximisation industries around oil, gas, hydro and fishing reserves. This re-alignment of Scotland's economic capacity and use of resources would, Riddoch argues, place Scotland in a strong position to function independently from its UK neighbours.

The outcome was a no vote, 55% to 45% (BBC, 2014). Although, it is worth noting that a significant swing occurred throughout the following year towards SNP support. Anderson and Sim (2011) outline that the shift towards SNP may indicate general disquiet in relation to the radical welfare reforms adopted by the 2010 minority Conservative/Liberal Democrat coalition government. In 2015, the UK elected a majority Conservative government and a subsequent general election took place in 2017, in which the Conservative government lost their majority.

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[9] Under the UK welfare reforms in 2012, the Spare Room Subsidy was removed in the social housing sector. This meant that households deemed to be under occupied were expected to increase their contributions towards the overall amount of rent. Disabled people have been twice as likely to be affected by the removal of the Spare Room Subsidy (Wilcox, 2014) since a spare room is often utilised for the storage of health-related equipment or to enable a carer to stay overnight. A fifth of the social housing tenants affected have accumulated rent arrears, while there is a lack of available one-bedroom properties in current social housing stock to facilitate downsizing (Power et al., 2014).

Turning to Norway, compared to Scotland there are differences in terms of history of political development and the present structure of governance. Norway is a sovereign state ruled by King Harald V. The Norwegian parliament is called the Storting. Elections are held every four years via an open proportional voting system and it draws upon a plural representation of nineteen administrative counties. These encompass Norway's current 428 separate municipalities (equivalent to local authorities in the UK). It should be noted that recent developments are moving towards greater de-centralisation of powers, improvements to local democracy and effective citizen-controlled services. For example, the coalition government of the Labour, Socialist Left and Centre parties in 2006 undertook administrative reforms that saw the transfer of more duties towards public roads move to the Norwegian counties in 2010. The 2013 minority coalition government also proposed municipality reform. The government argued for bigger municipalities with additional responsibilities and duties, the details of which were presented to the Norwegian parliament, the Storting, in Autumn 2017.

In 2013, Norway elected a centre-right coalition government. The smaller non-socialist parties strengthened their presence at the expense of some of the larger parties, such as the Progress party. In 2017, a minority coalition government between the Conservative party and the Progress party was officially declared. This was made possible through support from the two smallest, yet influential, Christian Democratic and centrist Liberal parties.

The area of equality policies in Norway is overseen by the Ministry of Children, Equalities and Social Inclusion (Krogenæs, 2015). General service-delivery and resource distribution is carried out by the NAV (Norwegian Labour and Welfare Administration). It provides a central point for information for people seeking employment or welfare advice, although service provision and delivery are affected by different regional procedures and governance decision-making across Norway.

Skeie (2004) argues that, in general, Norway has shifted towards a macro level neo-liberal ideology. For instance, Hanssen et al. (2001) note that the Norwegian political outlook had moved away from an ethos of universalism and towards a rationalisation of resources especially in relation to vulnerable groups in society.

Hanssen et al. (2001) continues that instead of those deemed vulnerable in society automatically receiving high levels of state assistance, rationing takes place to prioritise need and restrict eligibility criteria for benefits or services. Often, the prioritisation process involves attitudinal judgement aimed at stigmatising particular groups/individuals, especially those who may fall just short of welfare entitlements. As evidence of this Norwegian cultural shift, Hanssen et al. (2001) point out that a smaller proportion of Norway's population receive housing allowances (housing benefits) compared to the population proportions in Denmark and Sweden.

Writing in the area of welfare comparative research, Castles (2004) concurs that generally European welfare regimes are converging towards a neo-liberal system. However, he points out that due to embedded cultural, economic and political ideologies and frameworks, this convergence may take a considerable length of time, as defined by Esping-Andersen (1990), the Norwegian welfare system is upheld as an example of a social-democratic welfare model. For instance, in the area of comparative research on homelessness, the study by Benjaminsen and Andrades (2015) demonstrates the use of Esping-Andersen's theory in recent academic contributions. Benjaminsen and Andrades (2015) discuss that Norwegian research (for example, Dyb and Johannessen, 2013) highlight that the homelessness population within the social-democratic model is made up of predominantly people with complex needs, such as addictions, without associations with poverty as can be found in other welfare typology types.

Stephens and Fitzpatrick (2007) note that housing and health problems were overlooked by Esping-Andersen's (1990) welfare typology. However, Benjaminsen and Andrades (2015) point out that nevertheless comparative researchers still find his typology a relevant analytical framework. They note that the three model framework includes the considerations of socio-economic circumstances in particular countries, and enables the ability to track, assess and explain population trends associated with specific conditions under scrutiny.

Esping-Andersen's typology has also prompted theoretical developments in the area of comparative research. In addition to his typology, a southern European model, sometimes referred to as the 'Mediterranean' welfare regime has been

suggested whereby the role of the family and rudimentary social benefit systems characterise the nature of welfare (Leibfried, 1992; O'Sullivan, 2010). Extension of the European Union to encompass the post-socialist countries of Central and Eastern Europe has led to debates concerning their integration into the welfare typology (Draxler and Van Vliet, 2010).

### 2.3.2 Welfare Regime Approaches to Independent Living

The Derbyshire CIL in the UK was fundamental for the development of a framework through which disabled people's citizenship outcomes in Scotland and Norway can be assessed. The Derbyshire CIL set out to define priority needs for disabled people that could be acknowledged and supported at a macro (national) policy-making level. This led to the development of disabled people's 7 Needs of Independent Living. More recently, these were expanded to the 12 Pillars of Independent Living (Spectrum, 2016). Morris (2005) argues that regardless of a country's welfare regime type, disabled people's access to these various components of independent living will not be achieved until the underpinning dilemma of the citizenship debate is addressed. Namely, an individual's right to support is another individual's obligation and participation as a tax payer. Of the 12 Pillars of Independent Living, the central pillar within this debate is disabled access to an adequate income level to facilitate independent living.

Social policies in Scotland and Norway have taken two forms: distributive, such as educational or employment programmes, and regulatory, such as property construction standards or health and safety. As discussed above, there are values attached to particular welfare typologies and these values shape interpretations of the disabled citizen. Morris (2005) points out that for an inclusive society to adopt a citizenship of personhood, regulatory policies need to be put in place to enforce disabled peoples' rights to all areas of life. Hvinden and Halvorsen (2003: p.301) point out that regulatory policies aim to remove barriers to full participation for disabled people, and promote equal treatment in different contexts, for instance, through preventing and combating discrimination on the grounds of disability, although full potential often goes untapped due to the following reasons:

- Regulations have mainly been presented as recommendations and advice to the relevant actors, that is, they have not been binding or obligatory, and the sanctions against those who do not follow the regulations have been weak or non-existent.

- Regulations have contained formulations that are general, vague, discretionary and open to different interpretation, or no supporting administrative rules and authoritative operative guidance have been issued.

- Regulations are not followed up systematically and consistently by supervisory agencies that have the task to monitor the degree of compliance and sanction cases of non-compliance, or these agencies are too willing to grant dispensations or exemptions.

- Few, if any, formal complaints under the regulations are filed, and few cases are taken to court, for instance for reasons already suggested.

- There is a general lack of knowledge about the regulations and their implications among the relevant parties, not only people with impairment and their organisations, but also among, for instance, employers, trade union representatives, planners, architects and lawyers.

(Hvinden and Halvorsen, 2003: p.301)

On the other hand, redistributive policies also face challenges with discord around the appropriate level of an income to facilitate independent living. Hvinden and Halvorsen (2003) elaborate that across Europe this approach has received criticism for high expenditure and economic passivity, because of the financial disincentives to work due to generous benefit rates. Therefore, some people support cutbacks in those areas, with reduced duration and overall levels of payments accompanied by tighter eligibility and conditionality for continued receipt and/or stricter enforcement for people to participate in activation schemes.

Hvinden and Halvorsen (2003) continue that disability related benefits are often beheld as insufficient, ineffective or too weakly coordinated by the responsible

public agencies. Achievements of cost cutting and consistent public policies for people with impairments, referred to by the Nordic countries as the principle of sector responsibility, remain rare or unconvincing. Those with severe impairments tend to be disadvantaged in particular. There are also imbalances within the disability policy area, with too much emphasis upon administrating particular schemes for income maintenance or services for people with impairments, and not enough emphasis upon the removal of barriers against equal participation in society and work. More practical measures need to be implemented by national and local authorities, such as ensuring disabled people have access to personal assistance. Hvinden and Halvorsen (2003: p.303) summed up that overall:

> *"...too much emphasis has been given to user or patient perspectives on people with impairment, at the expense of a more general citizen perspective. As a result, the marginal status of people with impairment is reproduced, in spite of the espoused objectives of inclusion and equality."*

In concurrence, Bickenbach and Cooper (2003) highlight that at a macro (national) level, greater attention is required in relation to the measurement of independent living outcomes. Going back to the 12 Pillars of Independent Living, outlined in section 2.1.2 Independent Living and Social Policy, their assertions bring in to focus not only securing disabled peoples' rights to all areas of life but, designing effective monitoring mechanisms that present impact upon lived experiences of disablement. Within this context, Bickenbach and Cooper (2003) highlight the challenge of needs-led and rights-led policies. They point out that these approaches often have eligibility criteria based on thresholds that are arbitrary and artificial, especially since the needs of two individuals with the same impairment may differ. However, they continue, eligibility criteria and thresholds are expedient forms of measurement that enable use as political and economic justifications towards levels of expenditure on vulnerable groups, particularly those groups deemed deserving or non-deserving of welfare. Bickenbach and Cooper (2003) argue for the adoption of participation indicators. These provide evidence-based policies that are founded upon measurable outcomes at a micro, lived experience

of disablement level so that disabled people can inform effectiveness of addressing inequalities. As they point out:

> *"Instituting a 'rights-based disability policy' may be a successful political gesture, but without outcome measures and programme assessment it is a futile one. The reluctance that responsible sectors of governments have to move towards evidence-based performance assessments of their policy is one of the major reasons why rights-based policies for services and compensation fail."*

Within the debate surrounding what constitutes an appropriate level of income to support disabled people's access to independent living, an important issue is the potential introduction of an unconditional basic income. Welfare states aim to ensure a reasonable standard of living for people with a minimal level of disposable income, but subject to conditions. The unconditional basic income is a generous approach, which is seen as a radical alternative (Bay and Pedersen, 2003).

There are differences across the Nordic countries, with Denmark having arguably the closest to an unconditional basic income, whereby it has adopted a flat rate approach for benefits. Norway can be viewed as a compromise between the flat rate Danish model and Sweden's income-based model, with proportional payroll taxes (as opposed to general taxation) for social security (Andersson, 2000). A basic income can be perceived as a logical progression from the current Norwegian generous universal entitlement model, but it has not been followed through. Bay and Pedersen (2003: p.5) speculated that this may reflect its discord with the Scandinavian welfare tradition:

> *"...a strong emphasis on work ethics and the belief that full employment, high labour force participation and an egalitarian wage structure can be simultaneously achieved by way of adequate economic and labour market policies."*

### 2.3.3 Meso Level Governance

In this section, attention turns to meso (organisational) level governance and the interconnections with CILs. Firstly, 'Meso Level Governance' provides an exploration of Lowe's (2004) governance analysis will outline the ways in which meso level governance can provide insights or impact upon other tiers of society. 'The History of CILs' discusses the development of CILs across Europe since these user led organisations act as organisational forms of empowerment for disabled people. 'CILs and Co-Production' rounds off the background context to meso level governance, the role of CILs and service user involvement by reflecting upon the policies and practices in place to enable a co-production approach. An effective co-production approach, as will be highlighted, will enhance the ability of individual CILs to influence macro (national) decision making processes.

### Meso Level Governance Theory

Lowe (2004) has asserted that research should pay more attention to meso, organisational level governance analysis. Its main strength is that it captures different types and interconnections of communication across macro and micro tiers within societies. These networks are what Lowe (2004) refers to as the engine room of the modern British polity. As he went on to explain, inter-organisational partnerships or relations can be fairly autonomous from the state. However, the state can indirectly or imperfectly steer these.

Prior to Lowe's (2004) publication, Ratcliffe (1998 and 1999) conducted research into socially excluded minority groups. Ratcliffe puts forward that meso level analysis is best placed to uncover exclusion in terms of processes with, for example, people's lack of access to certain information. Therefore, Ratcliffe (1999) has asserted that research needs to attend to the identity of the excluded, what they are excluded from and how processes exclude. A meso level approach gains insights from both structural and agency levels: a structural level perspective emphasises the separation of a group from mainstream society, whereas an agency level explanation emphasises an individual's plight to seek separation/integration.

The first part of this chapter outlines that definitions of independent living and the social relational model of disability were developed through the collective action of disabled people. For example, many Centres for Inclusive Living across Europe were founded during the 1980s by early Independent Living Movement activists. Hirst (1994) has proposed that voluntary organisations, such as CILs, are best situated at the sharp end of practice to deliver, design and mentor provision of services for disabled people, instead of the state. The state is too inflexible and distant to keep abreast of diversity of needs (Elstub, 2006). The key component would be deliberative democracy. deliberative democracy, as Elstub (2006explains, combines democracy through collective decision-making, as well as *deliberative* decision-making processes through which all parties involved contribute towards debates before reaching a consensus.

However, Marian Barnes (2002) challenges these assertions. She argues that this approach assumes democracy throughout regulatory or funding frameworks and fails to resolve issues around equality of access or equality of governance. She continues that many disabled people working within organisations such as CILs can, for example, hold political views that could confuse relations with other bodies or processes. She concludes that service user participation requires diversity, not only amongst stakeholders, but in the ways that deliberation takes place, i.e. the power relations and representativeness.

### *The History of CILs*

Scotland has two CILs, the Glasgow Centre for Inclusive Living and the Lothian Centre for Inclusive Living, while Norway has one CIL, called Uloba. These are formal frameworks of user-controlled bodies, not-for-profit, based upon cooperative style governance, and that place peer support at the heart of operations with services run by disabled people, for disabled people (Independent Living Institute, 2016). Christensen and Pilling (2014) note that this was in response to policy ambiguities around the notions of choice and control:

*"Choice' and 'control' are rarely defined, often used together and sometimes interchangeably, in policy documents and the literature. It is often assumed that 'choice' (the power to select out of a greater number) provides control. In essence, personalised services are about tailoring services to individual's needs and preferences rather than - as has historically been the case in earlier service provision - fitting individuals into existing service provisions"* (Christensen and Pilling, 2014: p.479).

Shortly after the completion of fieldwork for this doctoral research, Roulstone and Hwang (2015) produced a historical account of CIL's beginnings under the influence of the Cooperative Movement. The cooperative form of governance offers the key elements of empowerment that are attractive for CILs, namely, access to information, inclusion and participation, accountability and local organisation (Roulstone and Hwang, 2015). The International Cooperative Alliance defined a cooperative as:

*"An autonomous association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations through a jointly owned and democratically controlled enterprise"* (International Co-operative Alliance, 2016: n.p.).

Table 2.6 presents the three main models of cooperative organisations in the disability field. Roulstone and Hwang (2015) discuss a case study of STIL (the Stockholm Cooperative for Independent Living) in Sweden. This was one of the first established CILs in Europe and has been a role model for many subsequent European CILs. After inspiration from the Global Disability Movement in 1984, STIL started a pilot of user-controlled personal assistance in 1987, despite opposition from Swedish political parties and the existing Swedish Disability Movement. In 1989, STIL services were made permanent and it has become a leader for the ethos of independent living across the world.

STIL introduced the concepts of self-determination and self-representation to Swedish disability politics and welfare policy. At a macro level, parameters for access to PA services designated that at a micro level, an individual requires a

minimum of twenty hours of support a week. Adopting a cooperative ownership model, Roulstone and Hwang (2015) reported that 19 000 disabled people were using direct payments in Sweden, and that approximately 60% of STIL members self-direct their support. Disabled cooperative members pool their state insurance funds for PA services in the form of direct payments. STIL hires PAs who are supervised by the individual members, and cover the home and workplace.

**Table 2.6 Cooperative Types in the Disability Field and Key Characteristics**

| Cooperative Type | Key Characteristics |
| --- | --- |
| Service user cooperative | The cooperative may contract with self-employed PAs or itself directly employ support staff. Service users would join the cooperative as they might join a community organisation or club, and have the right to select their own support worker from those on offer by the cooperative, recruit a PA and introduce a worker of their choice to the cooperative. |
| Multi-stakeholder cooperative | This has a membership of service users, staff and community organisations. |
| Employee-owned cooperative | Services are contracted from an employee-owned home support provider. Service users would agree to the support provided by the cooperative and would negotiate the practical arrangements themselves. The support worker and the service user would be free to negotiate changes to these arrangements within the agreed framework. |

Source: Co-operatives UK (2004, cited in Glasby and Taylor, 2006)

Peer support formed the heart of training new STIL members on how to manage PA services, as well as provide informal problem-solving strategies to maintain a good quality system. The benefits of peer support have been corroborated by studies such as Davidson et al.'s (1999) research regarding mental health. This study highlighted the way that institutional settings, such as hospitals, can nurture informal mutual peer support networks and how role models were particularly important for people moving out of institutionalised care to assist with coping strategies and provide feedback on life circumstances.

A democratic election process means that STIL members need to be voted on to the cooperative's board. The director points out how the cooperative worked:

> *"The co-operative charges a certain price per hour of services. The local government or the national social insurance pays each member a monthly amount that covers the cost of the numbers of hours that he or she needs. The funds are paid to the individual's subaccount in STIL. Thus, each member has a budget that s/he has to administer. The funds may be used for personal assistance only and have to be accounted for. The budget covers assistants' wages including compensation for unsocial hours, social insurance (avoiding the grey economy), STIL's administrative costs as well as the user's expenses for accompanying assistants"* (cited in Roulstone and Hwang, 2015: p.855).

Therefore, CILs emerged with the objective to protect the interests or needs of disabled people. Roulstone and Mason-Bish (2013) discuss the ways that the needs of disabled people can be overlooked or placed as lowest priority at a macro level. They drew attention to the current hierarchy of hate crime in the UK where mainstream support mechanisms often fail disabled people. They note that in order to receive protection or support, disabled people are required to be designated as recipients of social care. Such practices centre on the conception of vulnerability which, Roulstone and Mason-Bish (2013) have asserted, clashes with rights-based perspectives. For instance, under the social relational model of disability (Thomas, 1999), macro policy assumptions centred around the notion that disabled people are weak detract from disabled people's human rights at a micro level to enjoy access to public spaces or services unmolested or un-harassed.

CILs also came to challenge existing forms of support provided by disability related organisations. Although these acted as buffers between the state and disabled individuals (Walmsley, 2000), they tended to be, as Roulstone and Hwang described, "...not based on shared ownership and control and may perpetuate paternalism" (Roulstone and Hwang, 2015: p.851).

Many of these disability related organisations did not adhere to the ethos of independent living. Oliver (1990) characterises such bodies as belonging to one of four categorisations: partnership/patronage (organisations for disabled people, often charities working as consultants or on behalf of statutory authorities); economic/parliamentarian (organisations for disabled people, single-issue bodies lobbying for mainly economic matters or research); consumerist/self-help (organisations of disabled people, problem-solving and may not be political); and populist/activist (organisations of disabled people, political in nature and emphasise collective action/consciousness raising).

Arnstein's (1969) ladder of citizenship participation (Figure 2.1) is a well-established model of degrees of service user involvement. Centres for Inclusive Living aspire to attain the top rung of empowerment. The upper rungs that make up citizenship empowerment embrace the ethos supported by both the social model and social relational model of disability. This is where disabled people control decision making, especially in relation to resources or services that affect their access to independent living.

The lower rungs of the ladder, nonparticipation and tokenism entail a medical model approach; disabled people are objectified and if their views are recorded, they tend to be ignored. Oliver (1990) observed that other disability related organisations tended to function at these lower rungs with tokenistic involvement. Walmsley (2000), for instance, examined the history of two UK based volunteer organisations in the area of learning difficulties and their approaches towards the ethos of independent living. Both fitted the profile of partnership/patronage entities (Oliver, 1990), and they found that neither challenged the status quo nor advocated for the development of rights of people with learning difficulties. In particular, during the early half of the 20th century, the Central Association for Mental Welfare viewed learning difficulties as shameful. It worked with the government and local authorities to ensure that people with learning difficulties were supervised, preferably within institutional settings, and were sterilised.

**Figure 2.1 Arnstein's Ladder and the Degrees of Citizen Participation**
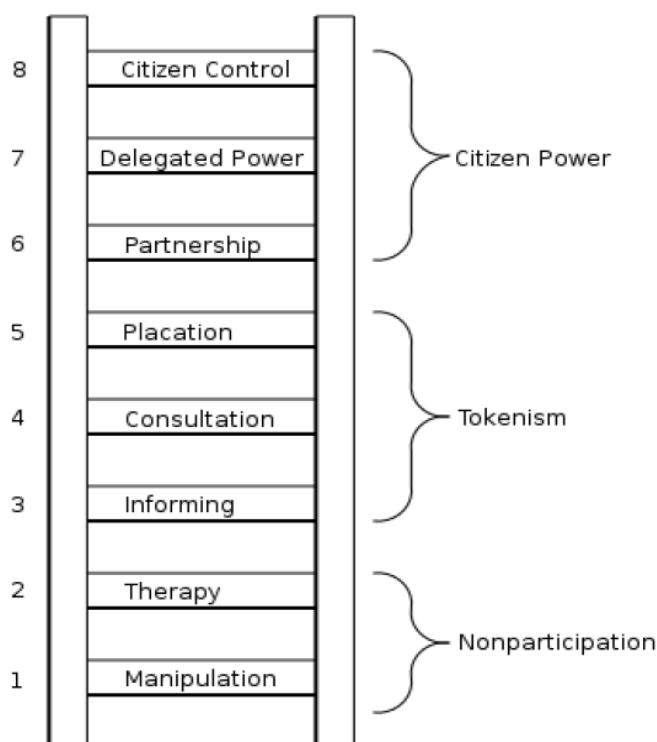


Source: Arnstein (1969)

Additionally, in 1946, the National Association of Parents of Backward Children (now known as Mencap) campaigned for better quality of community services. The members were parents of children with learning difficulties who the local authorities had designated as unable to benefit from schooling. Although they tackled the social prejudices around mental health conditions, they failed to recognise their children's right to live in their own homes with control over their own lives.

According to Roulstone and Hwang (2015), to date, within the UK there has been a lack of practical implementation of a commitment from the UK government for a user led organisation in each locality. As the Social Care Institute of Excellence (2009) pointed out, this pledge was outlined in the Prime Minister's Strategy Unit report Improving the Life Chances of Disabled People (2005) and re-stated in the 2007 Putting People First policy document (HM Government, 2007). The Office for Disability Issues (2013) depicts the benefits CILs make to disabled people's access to independent living and the advantages for service providers. Barnes (2007) highlights some challenges that have faced, and still face, the future of CILs. Firstly,

disability organisations have been incorporated or co-opted into government action due to funding opportunities, or to gain favour from policy-makers. However, such actions can distance CILs from their users and original objectives. Secondly, there is a significant lack of representation of disabled people within senior positions in organisations in the charity sector. Attempts to address this issue in recent times have been met with scepticism and charges of tokenism (Oliver and Barnes, 2012).

Roulstone and Hwang (2015) conclude their discussion of the history of CILs by raising questions around their role in the future delivery of welfare services. Firstly, they highlight the need to examine ways that national and local authorities can utilise collective solutions to welfare resources issues, for example, should such organisations be entitled to core funding, as is the case with other businesses involved, such as public energy or agriculture? They also ask whether the time is right to test out hybrid assumptions that lie behind personal entitlement versus collective use. In doing so, this may provide an effective strategy to promote a much needed economic diversity.

### *CILs and Co-Production*

The historical account of CILs development across Europe highlights the significant role of service user involvement in order that individual CIL organisations are able to challenge macro (national) and meso (organisational) policies and practices within a country. Buick et al. (2015) note that in order for organisations and policy-making to attain the highest level of service user involvement, a co-production approach must be adopted. In Scotland, the notion of co-production has entered political rhetoric during the past decade as a means to empower disabled people. Recent examples of co-production in Scottish policy are the Dementia Strategy 2013-2016 (Scottish Government, 2013) and the implementation of Scotland's National Action Plan for Human Rights 2013 - 2017 (Scottish Human Rights Commission, 2013).

In relation to social care, a co-production approach was embraced by the Public Bodies (Joint Working) (Scotland) Act 2014. This act seeks to integrate adult health and social care services to enhance deliver, as well as provide statutory

requirements for strategic planning. During strategic and commissioning processes, there is a legal requirement to include users of services. Users of services covers carers, patients/clients, organisations which provide services and professionals. It is envisaged that the co-production approach towards the provision of social care in Scotland, through greater user involvement, will result in a coordinated health and social care system that delivers appropriate services and support to those In need, at a time when most required.

As the co-production ethos and approach is relatively recent in gaining macro (national) level endorsement, steps have been taken to provide guidance and advice in regards to the implementation of co-production. The Co-production Network in Scotland website, for instance, contains resources, networking opportunities and case studies on the co-production approach (Scottish Co-production Network, 2016). The materials include tips on steps to help identify potential co-production projects and methods to evaluate existing co-production projects, such as the jigsaw framework towards change management.

The Social Care Institute for Excellence (SCIE) asserts that instead of focusing attentions on producing a precise definition of co-production, the co-production approach should be viewed in terms of principles (SCIE, 2009). These principles are equality, diversity, accessibility and reciprocity.  A co-production approach should include the following key features: define people who use services as assets with skills, break down the barriers between people who use services and professionals, build on people's existing capabilities, include reciprocity (where people get something back for having done something for others) and mutuality (people working together to achieve their shared interests), work with peer and personal support networks alongside professional networks and facilitate services by helping organisations to become agents for change, rather than just being service providers.

In terms of disabled peoples' access to independent living, the Independent Living in Scotland (ILIS) highlights the attitudinal and practical prerequisites that enable co-production. ILIS run an online co-production toolkit (Independent Living in Scotland, 2016) containing sections that cover different aspects of co-production,

such as definitions and case studies. The Toolkit also outlines practical considerations to address potential access issues for disabled participants. For instance this includes: access (materials in alternative formats, induction loops and wheelchair access), location (neutral venue and associated costs), communication (method and how often between meetings) and background information (enough information so that people understand the context of the project and the overall objectives).

### *2.3.4 Micro Level Governance*

Thomas (1999) recognises the lived experiences of disablement at a micro, individual level. Thomas points out that micro lived experiences of disablement are interconnected with macro and meso factors. For instance, during the 1980s some disabled people highlighted that their micro level lived experiences of disablement contained common issues and challenges. Under the Derbyshire Centre for Inclusive Living, disabled individuals formed a meso level collective that produced the macro 7 Needs of Independent Living. The 7 Needs of Independent Living were later developed into the macro 12 Pillars of Independent Living (Spectrum, 2016).

In line with a shift towards a neo-liberal framework across most countries in Western Europe since the 1980s, Pearson et al. (2014) point out that in parallel the provision of social care services and support have shifted towards an agenda of personalisation. Personalisation, as Duffy (2011) has noted, denotes that an individual makes choices about the nature of their support package and can opt to receive direct cash payments. However, this shift in governmental perspective towards notions of personalisation has been viewed with scepticism in a climate of austerity measures. O'Brien (1999 and 2001) notes that the language of choice, individualised budgets and person-centeredness, can cloak cuts to resources. For instance, resource cuts in the UK have depressed wages for personal assistants and have left them vulnerable to exploitation or with the stigma of being seen as having a lower value within society (Rummery and Fine, 2012).

There have been two main influences towards the development of personal assistance. Beresford (2009) highlights the differing ideologies exhibited by Direct

Payments and Personalised Payments. The former emerged from the Disabled People's Movement. It embraced the social model of disability and a desire to equalise opportunities and increase independent living. The latter grew from professional-driven changes due to criticism of the welfare state and its inability to promote independent living, and emphasises an integrated approach opposed to the removal of discriminatory barriers within society.

The ideology of personalised payments has been the most influential upon recent social policy developments. Askheim (2008) notes that cross-political support for the notion of Self-directed support has been achieved because it appealed to a market-based consumer stance, and to a radical civil rights perspective. Although no studies have specifically examined Scotland and Norway's personal assistance, Christensen and Pilling's (2014) research explores what differences have been found when policies of personalisation are implemented in a social democratic or in a liberal context. They focus upon cash-for-care in Norway and England (another UK country that is influential to Scottish policy-making under devolution).

Christensen and Pilling (2014) point out that in the English system, on one hand, users are faced with greater choice and control from the outset of the allocation process, and on the other, encounter greater insecurity due to variable circumstances under the simultaneously stimulated care provider market. The Norwegian situation shows more opportunities to develop choice for disabled people in a climate of a less diverse care provider market.

### 2.3.5 Personal Assistance in Scotland and Norway

As Pearson (2006) notes, voluntary organisations such as Centres for Inclusive Living and independent trusts play an important role throughout the development of personal assistance services in the UK. These bodies have been instrumental in acting as third parties for direct payments since in 1968; Section 12 of the Social Work (Scotland) Act allowed cash payments to be made available by local authorities only in exceptional circumstances. Despite this, compliance to the ruling by local authorities was low due to, as Pearson (2000) pointed out, a lack of knowledge among relevant practitioners of the guidance and only the former

Strathclyde region appeared to utilise this route for cash payments (Witcher et al., 2000).

Pearson et al. (2014) discuss the ways in which this particular geographical area of Scotland used funds paid by central government into an Independent Living Transfer (ILT) scheme to help establish an alternative model of indirect payments. Thus, the roll out of community care services, particularly in the wake of the Community Care Act 1993, was supported by this money and made available to local authorities across Scotland. During the 1990s, the Conservative government launched the Independent Living Fund (ILF). This facilitated another avenue for direct payments to be made to a specific group of disabled people: those with high support needs who had left institutional care and were relocated to live in communities.

In the UK, the first significant policy was the Community Care (Direct Payments) Act (1996), introduced through pressure from the Disabled People's Movement (Roulstone and Prideaux, 2012). The uptake was notably slower in Scotland (Priestly et al., 1999) and often benefited locomotion impaired individuals, in particular from middle class affluent areas, who were articulate and politicised (Leece and Leece, 2006). This slow development was attributed to several issues, including a lack of funding, lack of clarity in government guidelines, professional dominated planning and organising of services, negative assumptions concerning the capabilities of applicants and a lack of information and support for potential users (Duffy et al., 2010; Ellis et al., 1999; Spandler, 2004).

The Community Care and Health (Scotland) Act 2002 places a duty on local authorities to offer direct cash payments to eligible people to enable them to arrange and buy their own community and personal care. In the area of personal care in Scotland, the main drivers for policy change have come from the field of social work. The policy document, Changing Lives: Report of the 21st Century Social Work Review in Scotland outlined the notion of personalisation to be placed at the heart of the overall strategy for social care (Scottish Executive, 2006).

In 2006 the Changing Lives: Report of the 21st Century Social Work Review in Scotland, firstly gave emphasis to the role of prevention. A goal was to build an individual's capacity to manage their own life choices. Secondly, users with complex cases were facilitated to design their own care package solutions. Thirdly, personalisation was viewed as a mechanism to provide choice. Following on from this momentum, in 2010 the Scottish Government published a Self-directed Support Strategy which sought to increase the uptake of Self-directed Support through direct payments, providing flexibility, choice and control to more individuals (Scottish Government, 2010). The Self-directed Support Strategy (2009) outlines that the aim of Self-directed Support is to increase the ability of disabled individuals to live independently at home for as long as possible without the necessity of moving into residential care institutions.

Pressure from the Association of Directors of Social work and the Disabled People's Movement in Scotland culminated in the Social Care (Self-directed Support) (Scotland) Act 2013, which states that local authorities in Scotland must give disabled people four choices: direct payments, directly support disabled people's social care needs, let the local authority direct their support or a combination of the previous three options.

In Scotland the implementation of Self-directed Support in practice has drawn upon findings from pilot studies. The piloting of individual budgets (IBs) in 2003, for instance, sought to establish user-determined support solutions for care packages. Additionally, Etherington et al. (2009) outlined the *In Control* demonstration project piloted in North Lanarkshire, Scotland, with sixteen people and their families. This emerged in response to criticisms of the existing system where disabled people were viewed as passive recipients. The status as passive recipients of care meant that disabled people experienced services that lacked flexibility, lacked transparency of entitlements, held little incentive for family or friends to contribute, and users were often slotted into existing services. Therefore, the project concentrated upon self-assessments of need by users of their individual budgets and enabled them to utilise resources that met their unique circumstances.

Etherington et al. (2009) outline that the payments associated with an individual budget can be managed by either the service user, a representative or the local authority. They assert that:

> "The important thing is that the person and those close to them have control of the money. Knowing how much money is available and what outcomes must be achieved, the person and their family can take control of their individual budget and plan how it is used." (Etherington et al., 2009: p.2).

However, the local authority makes the final decision in relation to the approval of proposed individual support plans.

The pilot project concluded that the key ethos of equity and transparency was attractive for all stakeholders. It was proposed that the In Control approach should be the way forward for care packages across Scotland. However, it highlighted the need for a step-by-step guide and more clarity around resource allocation systems.[10]

Duffy et al. (2010) assert that there are seven key steps to Self-directed Support (Figure 2.2) and argue that the area of social care should adopt a Conditional Resource Entitlement approach within social policy and resource distribution. They point out that, for instance, this already applies in the areas of prescription medicines and local housing allowances.

Turning to Norway, user-controlled personal assistance for disabled people, (BPA (Brukerstyrt Personlig Assistanse)) has gradually gained political support over the past thirty-five years. It began with a pilot project through the Norwegian Association of Disabled People that inspired the development of the current Norwegian Centre for Independent Living, Uloba (Independent Living Institute, 2011). This user led cooperative, plus municipalities, dominate the provision of personal assistance in Norway. The Municipal Health Act of 1982 first identified that the Norwegian municipalities were responsible for long-term care services.

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[10] A Resource Allocation System (RAS) takes the form of a simple, supported self-assessment questionnaire that is used to let people know early on in the process how much money is available to them from the local authority to fund their support. It also clearly states the intended outcomes of their support plan. The RAS gives an indication of the maximum amount of money that should be in a person's individual budget and what it must achieve.

This devolved approach to governance reflects that each area can customise services that suit local needs, local conditions and local political orientations.

User-controlled personal assistance became legalised in Norway under § 4-2 of the Social Services Act (2000), which states that services include:

*"…practical support and training, including user-controlled personal assistance, to those with special needs of assistance due to illness, impairment, age or for other reasons."*

Guldvik (2003: p.123) points out that the position of personal assistance service within Norwegian society assumes the following attributes:

1. Same category as home help but key differences are: personal assistants work for one individual user only;

2. The user participates in the recruitment process;

3. The user is the manager of the work; and

4. Personal assistants are expected to carry out services both in and outside the home.

During the 2009 Norwegian election, the Labour party, which was the opposition party at the time of writing this thesis, supported a bill to implement user-control over choice of personal assistance provider. However, it retracted by proposing disabled people should be viewed as passive recipients of care – denoting that personal assistance services would be controlled and delivered by municipalities without the empowerment of service users to make decisions relating to the nature of their care needs. Additionally, the concepts of user-control was linked to home-help and personal assistance to medical care services. Bente Skansgård, Uloba founder, revealed in an interview in 2011 with the Independent Living Institute in Sweden that the adoption of this professional dominated, medicalised perspective of personal assistance was a step backwards for disabled people's access to independent living in Norway.

**Figure 2.2 Seven Steps to Self-directed Support**

> **Step 1** - everyone is told their financial allocation - their personal budget - and they decide what level of control they wish to take over their budget.
>
> **Step 2** - people plan how they will use their personal budget to get the help that is best for them; if they need help to plan, then advocates, brokers or others can support them.
>
> **Step 3** - the local authority helps people to create good Support Plans, checks they are safe and makes sure that people have any necessary representation.
>
> **Step 4** - people control their personal budget to the extent they want; there are currently six distinct degrees of control: from direct payment at one extreme to local authority control at the other.
>
> **Step 5** - people can use their personal budget flexibly: they can use statutory services (the cost of which is taken out of the personal budget) and other forms of support; if they change their minds they can redirect their personal budget to more appropriate forms of support.
>
> **Step 6** - people can use their personal budget to achieve the outcomes that are important to them in the context of their whole life and their role and contribution within the wider community.
>
> **Step 7** - the local authority continues to check that people are okay, shares what is being learned and can change things if people are not achieving the outcomes they need to achieve.

Source: Duffy et al. (2010)

An interview with Jan Andersen in 2011 discussed personal assistance in Norway and highlighted that the social care system faces potential resource cuts across municipalities and a general lack of user-controlled personal assistance (Westberg, 2011). Between 2002 and 2010, personal assistance increased from 600 to 2 300 users, with each user receiving, on average, thirty-three hours of support per week. The Norwegian state covers social care costs that exceed £74 000 per year for each municipality, while some municipalities also charge disabled people a contribution towards home-help hours within personal assistance packages if users are in receipt of certain levels of income. It is also worth noting that family members obtain care subsidies and relief where they participate in personal assistance duties.

The introduction of the Municipal Health and Social Care Act (2011) signalled progress for disabled people's access to independent living in Norway. User-controlled personal assistance was fully recognised in section 3-8. Here, it obliged municipalities to offer user-controlled personal assistance in terms of support

options for disabled people and training. According to Johansen et al. (2010), 54% of disabled people in receipt of user-controlled personal assistance had municipality delivered services, the user led cooperative Uloba delivered personal assistance to 33% of users, 11% of Uloba users chose their own personal assistants, and did this on their own and 2% engaged private companies.

The Municipal Health and Social Care Act 2011 stipulates that although municipalities are obliged to secure quality services, they do not necessarily need to act as a service-provider. Therefore, Christensen and Pilling (2014) have pointed out that a significantly lower level of municipal services are delivered by other providers: only 8.1% of the sector's services are purchased from private actors (SSB, 2012). Gammelsæther (2006) has observed that municipalities are more likely to engage other contractors in relation to the monitoring of performance.

Christensen and Pilling (2014) have asserted that strong social-democratic countries such as Norway should demonstrate well-developed systems that connect citizenship rights with state provision of necessary services. However, an examination of personal assistance in Norway illustrated that this is not the case. Disabled people in Norway do not have a right to personal assistance. Under the legislation, it is municipalities who determine whether a person is eligible and authorise the exact amount of support within a care package. As Christensen and Pilling concluded:

> *"In this sense the Norwegian system represents a paternalistic bureaucratic system, giving power to municipalities (here equalling the state) primarily and only secondly to the users, at the end of an assessment process"* (Christensen and Pilling, 2014: p.490).

Full user-control over all aspects of personal assistance is tenuous in both Scotland and Norway. For example, professional gatekeeping of services, referred to as the professional gift model by Duffy (2011), affects disabled people's access to personal assistance. Glendinning et al. (2002) recommended the following improvements to social care that apply to personal assistance provided in both countries. Namely, they highlighted that personal assistance should be equipped

with a good level of pay, investment of funding by the state, supervision and training opportunities. The particular areas for development in Scotland and Norway would be around the establishment of accredited qualifications, user led training courses and a collective for peer support amongst personal assistants.

Ellis et al. (1999) also point out that discussions around rationing are not a new phenomenon and that within societies, need and demand tend to always outstrip supply. Therefore, writers within disability studies have put forward theorising that challenges the current neo-liberal perspective on citizenship and approach towards personal assistance present in Scotland and Norway. They argue that only by reconstructing societal relationships with the needs of physical bodies and the role of care can disabled people access independent living.

Echoing Thomas' (1999) emphasis upon impairment effects at a micro level of analysis, authors such as Sevenhuijsen (1998), Morris (2001) and Hamington (2004) have argued for ethics of embodied care. They point out that inclusion of the workings of the body is essential throughout the theorising of citizenship in order to develop a social ethics of care that is not devoid of corporeal considerations. This increases the sense of empathy as fellow human beings and, as proposed by Shakespeare (2000), makes care-givers more alert to potential abuse through the undertaking of intimate tasks for recipients. Care should not be viewed as a technical, objective chore devoid of ethics or morality (Rummery and Fine, 2012; Shakespeare, 2000). Hamington (2004: p.3) offers the following definition of the ethics of embodied care:

> *"...care denotes an approach to personal and social morality that shifts ethical considerations to context, relationships, and affective knowledge in a manner that can be fully understood only if care's embodied dimension is recognised. Care is committed to the flourishing and growth of individuals yet acknowledges our interconnectedness and interdependence."*

Rummery and Fine (2012) have also commented that there has not, as yet, been a systematic body of evidence to compare the policy equity outcomes for recipients of care across different welfare regimes. They call for a citizenship approach to

care. They asserted that without social participation, choice and control this can result in an environment of enforced gratitude from recipients and for services that may not necessarily meet all their needs. A reframing of care within a citizenship discourse, opposed to that of markets, would establish its role as a means of self-determination and social participation for both carers and cared-for. As they explain (2012: p.337):

> *"Carers need to be free to choose whether or not to care, and how to provide the labour of care, and care-recipients need to be free to choose the level and type of care they receive, and from whom."*

Guldvik's (2003) study, for example, looked at personal assistance in Norway and found that personal assistants emphasise, to various degrees, the ideal of caring rationality or a service orientation model. A survey was distributed to half of the personal assistant population (around 680 people) in Norway during 1999 and there was a 70% response rate. The survey found that four out of five assistants stated that they were generally satisfied or very satisfied with their jobs. The majority viewed their relationships with users as a working relationship rather than a friendship. Key values emerged as communication, respect and tolerance.

Personal assistants also described problematic aspects connected with their job. Conflicts arose between service users and personal assistants, such as a desire for stable tasks/fixed hours, when users wished for flexibility, and a tendency for users to involve assistants too much in private affairs. This may help to explain why two out of five speculated that they would be likely to leave their job, whereas an equal proportion stated they would certainly continue, and one out of five planned to definitely quit their job.

Guldvik (2003), therefore, classified personal assistance into two typologies, to be regarded as polarities on a continuum. These were humanist and pragmatist profiles. Table 2.7 depicts the key characteristics of each, although Guldvik (2003) points out that this was based upon a small number of participants (thirty-six humanist and twenty-four pragmatists). However, such classification may help to match users and personal assistants in terms of effective partnerships, depending

upon their mutual desires and motives. This helped to inform later work, such as Ungerson (2005) who characterised the nature of care as either 'warm' or 'cold'. The former is a relationship that is intimate, familial and enduring, and the latter often occupational or professional, limited in time and focused primarily or exclusively on mental and physical well-being.

**Table 2.7: Characteristics of the Two Assistant Profiles**

| Characteristics | Pragmatist profile | Humanist Profile |
|---|---|---|
| Age | 30 years | 40 years |
| Education | College/university level | Upper secondary school level |
| Combining activities | Combines PA with study | Combines PA with work in municipal social care services |
| Plans for the future | Unsure or planning to leave | Remaining in the job |
| Heard about the job | Advertisement | Advertisement or through personal contact with user |
| Acquaintance with the owner | No previous experience | Knew the user before she started |
| Working hours | Short, part-time, less than 14 hours/week | Part-time, more than 14 hours/week |
| Degree of flexibility | High degree of flexibility | Medium degree of flexibility |
| Satisfied with basic working conditions | Relatively high degree of satisfaction | Medium degree of satisfaction |

Source: Guldvik (2003: p.129)

In conclusion, the discussion of personal assistance services in Scotland and Norway has demonstrated the evolution of one of the specific 12 Pillars of Independent Living (Spectrum, 2016) from a micro level impediment, through collective coordinated campaigning at a meso level, which leads to macro level policy change. The examples of the Glasgow Centre for Inclusive Living and Uloba were highlighted as collective entities to focus the interests of disabled people and support, either through direct campaigning or practical services, to implement changes for personal assistance services into policy. However, it has been argued that the current neo-liberal framework in both countries poses many challenges. Achieving legislative recognition that personal assistance is a right for disabled

people may involve the reconstruction of societal perceptions of citizenship and care.

### 2.3.6 Accessible Housing in Scotland and Norway

Another of the 12 Pillars of Independent Living is accessible housing. Within macro level welfare comparative research, interpretations of housing can be ambiguous and contentious around its status as a welfare resource. For example, housing can be viewed both as a public resource and as a market commodity (Kemeny and Lowe, 1998). Lowe (2004) has outlined some of the reasons behind the omission of housing by early welfare state analysts, including the complexities and adherence to a silo academic agenda (see Esping-Andersen, 1990; Wilensky, 1975).

For instance, Schmidt (1989) conducted one of the first international comparative studies to look at tenure strategies and political orientations. His statistical analysis uncovered no correlation between the degree of socialist party influence within national governments and the impact upon home ownership. There exists a strong correlation between national home ownership rate and welfare ideological orientation. Consequently, the more inclined countries are towards welfare consumption, such as sickness benefits or pensions, the more they are disposed to emphasise collective renting.

Earlier in the chapter it was discussed that the definition of disability emerged due to the onset of industrialisation (Oliver, 1990). During this particular point in history, people flocked to European cities to seek employment, and this mass urbanisation fostered poverty, rapid spread of diseases and poor housing conditions. Housing policies, to address the needs of the working class, were introduced across Europe towards the end of the 19th century in response to philanthropic and private initiatives to house a workforce from cradle to grave (Priemus and Dieleman, 2002). Although, as noted earlier, Oliver and Barnes (2012) pointed out those deemed unfit to work, such as disabled people, were previously segregated into specialist institutions or workhouse establishments.

Both Scotland and Norway have, therefore, mirrored a mixed institutionalisation approach towards the housing of disabled people (Kielland, 2010; Means et al., 2003; Tøssebro et al., 1996; Wansley, 2000). Public spaces have been designed without consideration of access for all (Bull, 1998) and today, accessible housing or adaptations are often portrayed as special needs outwith mainstream practices (MacFarlane and Laurie, 1996; Marks, 1999; Nielsen and Ambrose, 1998; Sapey, 1995; Sapey et al., 1999).

Within housing studies, there has been a raft of literature that draws attention to the ways in which housing shapes and gives meaning to everyday lives at a micro level (Saunders, 1989; Saunders and Williams, 1988). For instance, Saunders (1989) highlights that homes can be places for personal control and expression for some people. For many disabled people, though, their home can impede independent living or even impact negatively upon physical and psychological wellbeing (Imrie, 2004). Disabled people's experiences of housing can be characterised by communicational, financial, attitudinal, political and environmental barriers (Hemingway, 2011; Kielland, 2010). Newton et al. (2006) also highlight the need to contextualise housing within a wider picture of the external environment's accessibility and attributes towards individual well-being.

Maslow (1954) asserts that shelter is a basic survival need. Despite this, current low levels of accessible properties across Europe hinder societies to suitably house disabled citizens. Due to our aging populations with the associated increase in impairment levels, the pressure to provide adequate accessible properties will intensify (Adaptations Working Group, 2012; Kangas and Palme, 2005; World Health Organization, 2012). In Scotland, 65% of the current housing stock was built pre-1965 and 21% pre-1919, which pose challenges for accessibility (Sim, 2004). An estimated £10 billion is also required for general renovations and approximately 60% of accessible housing contains occupants whose housing does not meet their needs (Inclusion Scotland, 2008).

In the latter half of the 20<sup>th</sup> century, UK housing policies attempted to increase home-ownership, stimulate greater market involvement and, more recently, reverse a shrinking social-renting sector (Malpass, 2005; Scottish Government,

2010). For example, the strategy and action plan Homes Fit for the 21st Century (Scottish Government, 2011) proposed the abolition of the sale of social housing under the Right to Buy (introduced in the Housing (Scotland) Act 1980) and this was taken forward in the Housing (Scotland) Act 2014. It also supports the development of a Scottish Accessible Housing Register for disabled house seekers, based upon the Glasgow Centre for Inclusive Living's local online Accessible Housing Register. Generally, strategic planning of housing is delivered by the thirty-two Scottish local authorities. To date, six local authorities have opted to transfer their housing stock to housing associations (Anderson and Ytrehus, 2012). The national strategy on housing in 2011 encourages local authorities to build at least 10% of new properties to the accessible lifetime homes standard (see Appendix XIII). These legislative measures have sought to combat the financial,[11] property supply[12] and household composition[13] barriers (MacLean and Guy, 2015) faced, according to figures in 2014, by approximately 836 000 households with a disabled member (Scottish Household Survey, 2015).

Despite Norwegian housing space standards taking the lead in Europe (Wessel, 1998; Ytrehus, 2011) with mandatory universal design for all new built properties under the Accessibility and Anti-Discrimination Act 2009 (Universal Design, 2015), only 7% of Norway's housing stock was wheelchair accessible (Husbanken, 2012). Wessel's (1998) research noted an under-representation of disabled residents due to inaccessibility issues in the three main cities of Oslo, Bergen and Trondheim. As Wessel (1998) noted, housing is viewed as a social right in Norwegian society. It is controlled at a local level from provision to planning and from design to allocation (Sorvoll et al., 2009) under a national framework set by the 2013 coalition government. In 2009, the Anti-Discrimination Act introduced that all new properties in Norway must adhere to universal design construction standards (Weisman, 1992).

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[11] Financial/economic status: whether or not people can afford to buy a home or adaptions.
[12] Property/supply: availability of appropriate housing.
[13] Household composition: whether or not people live with a partner, children or parents.

Nielson and Ambrose (1998) point out that in Norway the very small public stock is utilised for the most vulnerable within society, including disabled people and those that lack knowledge of the housing system or have very low incomes. The Husbanken, a not-for-profit state-funded bank, provides higher subsidies for properties built to lifetime home standard, as well as working in conjunction with local municipalities to identify, for example, loans, grants and welfare benefits for disabled people seeking home-ownership.

In summary, accessible housing plays an important part within the holistic perspective of independent living (French and Swain, 2008). This section has highlighted the role of CILs or other stakeholders in disabled people's access to suitable housing in Scotland and Norway. Both countries have been affected by historical commonalities, such as the onset of industrialisation during the 1800s and 1900s. Disability at this time was defined as deviancy, and therefore, disabled people's needs were excluded from the physical construction of public and private spaces and places.

Although Scotland and Norway encounter a chronic shortage of accessible housing, the policy responses have differed. Scotland has a patchwork of legislative measures and regulations that encourage at most 10% of new properties in the public sector to be built to lifetime homes standard; whilst in Norway, the Disability Discrimination Act 2009 has introduced compulsory universal design for all public funded properties. The Glasgow Centre for Inclusive Living developed disabled people's access to suitable housing through the Scottish National Accessible Housing Register, whereas in Norway, the Husbanken, with peer support from Uloba members, provides the necessary support for disabled people to access home ownership. It is unclear to what extent CIL users benefit from CILs in relation to accessible housing, due to a lack of research around their experiences or views. However, the evidence would suggest that CILs provide valuable support to overcome existing financial, communicational and attitudinal challenges experienced by disabled people at a micro level.

### 2.3.7 Summary

To summarise, this section has highlighted that governance provides a useful mechanism through which to examine disabled people's access to independent living at different tiers of societies. As the social relational model of disability outlines (Thomas, 1999), an understanding and analysis of disablement is not possible unless attention is given to macro, structural factors, as well as micro, agency level explanations. For this research, macro denotes structural, national level decision-making; meso denotes organisational governance; and micro denotes agency level lived experiences of disablement.

At a macro level, Scotland and Norway exhibit differing approaches towards the distribution of resources required for independent living, and governance enables an exploration of such relationships (Wallace, 2009). For example, Esping-Andersen's (1990) welfare typologies provided a theoretical framework for comparing countries. Within this model, Scotland is characterised by a liberal welfare regime whilst Norway adheres to a social democratic welfare regime.

For both countries, one of the main challenges to social policies that are regulatory in nature is the extent of enforcement. In the Nordic nations, redistributive social policies have been challenged as being too generous and detracting attention away from the practical implementation of facilitators to eradicate discriminatory barriers and support disabled people to fully participate (Hvinden and Halvorsen, 2003). The social relational model supports Bickenbach and Cooper's (2003) discussion of a policy shift towards needs-led provision. This avoids a continual categorisation of impairment types so that disabled individuals meet specific criteria and instead places the focus upon the lived experience of disablement to identify support needs.

Similarly, debates surrounding a basic income would support a social relational approach towards addressing macro and micro level barriers for disabled people, especially in employment. Norway can be viewed as a compromise between the flat rate Danish model and Sweden's income-based model (Andersson, 2000) and according to Bay and Pedersen (2003), a progression towards a basic income has

been thwarted by a Norwegian cultural value of economic stability arising from a strong work ethic. However, this fails to take into consideration the attitudinal and structural barriers that hinder disabled people's participation in the workforce (Oliver and Barnes, 2012).

Lowe (2004) and Ratcliffe (1998 and 1999) have argued that meso, organisational level governance analysis enables an examination of who is excluded from society and the processes that lie behind exclusionary policies or practices at all tiers of society. This fits with the social relational model approach, whereby a multi-strata understanding of disablement is placed at its heart. An example of meso level facilitators for disabled people's access to independent living is the development of CILs. These collectives of disabled people running services for disabled people arose at an agency level from a shared frame of reference around the ethos of independent living and peer support (Roulstone and Hwang, 2015).

CILs came to challenge existing disability related organisations that fail to value disabled people as citizens or agents of everyday life decisions (Oliver, 1990; Walmsley, 2000). Traditionally, disability related organisations adhered to the medical model of disability (Drake, 1999) and adopted a tokenistic approach towards service user involvement; opposed to CILs that strive for full user-control (Arnstein, 1969). Roulstone and Hwang (2015) conclude that CILs provide a valuable opportunity to examine ways to increase disabled people's access to independent living through, for example, re-positioning their status in the eyes of the state to receive core funding or to pursue alternative forms of service delivery to meet demand under current resource constraints.

The 12 Pillars of Independent Living (Spectrum, 2016) include the areas of personal assistance and accessible housing. However, examination of micro level, lived experiences indicates that some pillars have attracted greater collective efforts, campaigning and policy change from among disabled activists. For example, Pearson et al. (2014) highlight that across Europe a neo-liberal approach towards service delivery poses challenges for disabled people's control and choice over personal assistance services.

However, access to independent living has been improved through pressure from disabled people for policy change such as the Community Care (Direct Payments) Act (1996) and the Norwegian Municipal Health and Social Care Act (2011). Although, neither country recognises personal assistance as a right and there have been calls for the incorporation of the ethics of care (Hamington, 2004; Morris, 2001; Sevenhuijsen, 1998) in line with the social relational model at a structural level to alter value systems around the care profession, and at an agency level to acknowledge the role of the body and fluctuations in health conditions.

Contrastingly, there have been fewer collective efforts amongst disabled activists to tackle accessibility barriers encountered through a lack of accessible housing, and consequently, they have yet to result in policy enforcement of cross-tenure property construction to universal design in both countries (Inclusion Scotland, 2008; Wessel, 1998). Such barriers have been outlined in terms of finance, supply of accessible housing and physical access, including the accessibility of surrounding environments (Husbanken, 2012; MacLean and Guy, 2015). As the social relational model would imply, at an agency level adherence to universal design would recognise a life course perspective of impairment: people can become impaired for short periods of time or can have health conditions that deteriorate and improve.

## 2.4 Conclusion

To conclude, this chapter presents the contextual history, policy development, research and practice that underpin disabled people's access to independent living in Scotland and Norway. The concepts of disability and independent living in both countries have been shaped by political, cultural and industrialisation changes, especially during the late 19th century and early 20th century (Oliver and Barnes, 2012). This period saw significant policy developments in relation to welfare. In order to reflect the prevailing approach to who was deemed deserving and undeserving of societal resources, the medical profession played a significant role in the detection of genuine or artificial cases of disability (Roulstone and Prideaux, 2012).

In doing so, the medical model of disability came to dominate the approaches to welfare policy and societal value systems around disabled people (Drake, 1999). During the 1970s the Independent Living Movement that originated in the USA began to influence the thinking of disabled activists across Europe (Hunt, 2001). This helped define independent living as a form of empowerment that gives disabled people control over their everyday life choices. The emphasis was not on how much a disabled person can do, but instead, focused upon what can be achieved with the appropriate support (Shakespeare, 1998). In the UK the Derbyshire CIL devised 7 Needs of Independent Living, which was expanded by Spectrum CIL in 2010 to form the 12 Pillars of Independent Living (Spectrum, 2016). Although current policy landscapes in Scotland and Norway testify that some progress has been achieved in this area, the evidence indicated that not all elements of independent living are yet perceived as rights for disabled people.

The concepts of disability and independent living have also been reconstructed through the emergence of the social model of disability (Oliver, 1990). This challenges the medical model and places the emphasis upon the removal of structural barriers to enable disabled people's participation within society. Such an approach assisted disabled activists to campaign for the introduction of the Disability Discrimination Act 1995 (UK), but it has been criticised for failing to incorporate agency level analysis and translate in to a coherent empirical framework for research (Oliver and Barnes, 2012).

Thomas' (1999) social relational model of disability put forward analysis of both structural macro and micro agency level explanations of disablement. Attention is given to psychosocial effects and a theory of impairment, alongside theories of disability (Abberley, 1987; Goodley, 2011). In Norway, the social relational model has taken precedence for theorising on disability (Tøssebro, 2004). However, this research seeks to adopt the social relational model to address a gap exposed in knowledge and research around the experiences and views (at the time of fieldwork, this is 2012) of disabled people, policy-makers and disability related organisations in relation to the first research question: what practices or policies facilitate or impede disabled people's access to independent living?

In the application of a social relational model, an integration with meso level governance analysis (Lowe, 2004) presents a useful approach through which to examine facilitators and impediments at different tiers of society in relation to disabled people's access to independent living. This approach captures the communicational interactions across macro, national policy-making and micro, agency levels with attention to relationships, partnerships and networks within decision-making structures (Lowe, 2004).

At a macro level, writers within disability studies, such as Simonsen (2005), have highlighted the benefits of a cross-national comparative approach and provide an emphasis on the history of disability, which furthers understanding and promotes theory-generating around mechanisms for social inclusion. Esping-Andersen's (1990) welfare regime types give a useful contextual lens for comparative research. At a meso level, user led Centres for Inclusive Living have emerged from collectives of disabled people, often involved with the Disabled People's Movement, to run services for disabled people by disabled people. At a micro level, it is evident that within specific areas such as personal assistance, one of the 12 Pillars of Independent Living, disabled people have engaged to create change in policy and practice (Pearson et al., 2014; Westberg, 2011), while other pillars, such as accessible housing, exhibit less of a coordinated response, although some studies have revealed numerous barriers to accessing independent living (Hemingway, 2011; Wessel, 1998).

However, at the time of fieldwork, the literature review identified a gap in the evidence base in relation to the second research question: in what ways do the governance structures of Centres for Inclusive Living enhance disabled people's access to independent living within societies? It is important to point out that Roulstone and Hwang (2015) subsequently published an exploration of the history of CIL's development in Europe. Roulstone and Hwang (2015) report the experiences and views of key staff involved with a CIL in Sweden. This research goes on to contribute the perspectives of Scotland's service users and Norway's co-owners.

An examination of the concept of citizenship within the social relational model reveals the societal values that underpin national and organisational policies and practices, as well as the lived experiences of disabled citizens. Since the inception of a social contract between the state and individuals during the 16th century, the concept of citizenship has been contested in terms of how it should be measured or operationalised (Hobbes, 1973; Locke, 1965; Marshall, 1952; Rousseau, 1913). Authors in disability studies have sought to reconstruct the notion of citizenship to facilitate access to independent living. For example, Morris (2001) has discussed the notion of the ethics of care. The ethics of care called for the recognition that emotional, bodily and everyday interactions constitute the practice of citizenship. Beckett (2006) expands upon Morris' argument by pointing out that societal values need to centralise vulnerability. The recognition of vulnerability within social policy acknowledges the meaning of personhood and constructs an infostructure to support a lifetime approach towards care.

This research aims to explore and to contribute the voices of disabled people to debates surrounding citizenship. This study seeks to address a gap in the knowledge and research around a person's sense of disablement. The focus is upon whether individuals identify as disabled or reject the label of disabled, and leads to the third research question: does the nature of self-identification affect disabled people's experiences of, and access to, independent living?

Overall, this literature review has highlighted that there has been a lack of research that combines the three core conceptual areas: independent living, citizenship and governance towards the analysis of disablement. Each area has contributed towards understandings of disabled people's access to independent living in different ways.

The following chapter goes on to present the research strategy and sets out the epistemological, ontological and methodological positions behind data collection and analysis for this study. It establishes the research aims that seek to uncover the type of information desired to explore the three core research questions that have emerged from the literature review.

# Chapter 3. The Journey

## 3.0 Introduction

> *"If you fail to plan, you plan to fail. The sources of quality research are skill, expertise and effort. The most important qualities of a researcher are humility, honesty and self-criticism. Practical resourcefulness, tolerance and persuasive diplomacy are just as important as technical skills for completing a successful comparative project. You plan, and then life happens."* (Ovretveit, 1998: p.121).

The literature review in the previous chapter outlined the journey that identified this study's central research questions from empirical and theoretical sources. This chapter will set out the ways my fieldwork outlined specific underlying research aims in order to gather the data required to address these central research questions. It presents my obligation as a researcher to be open about my epistemological (what constitutes knowledge), ontological (what is knowable) and methodological (how knowledge is revealed) positions (May and Williams, 1998; Ramazanoglu, 1989; Skeggs, 1994), and demonstrate that my choice of methods and approach towards data collection was logical and rigorous (Barnes, 2003). Doing so makes me accountable to my research sponsor, the Economic and Social Research Council (ESRC), and all my research participants.

During the research process, Layder (1982) identified three key questions to guide any study and these have shaped the structure of this chapter, which is divided into six sections. The first section, Research Methods, examines the research strategy and choice of methods in response to the question:

1. **What range or scope of explanation is required?**

As Dogan (2002) noted, method denotes either a research stratagem or a technique. The overall research approach was framed by Derek Layder's adaptive theory (1982; 1998; 2006). Adaptive theory combines the use of pre-existing theory and the generation of theory from data analysis. Layder's work supported a flexible

approach whereby my pre-existing knowledge inspired and shaped the research process, and themes highlighted by research participants focused attention upon specific areas or issues within the topic of independent living for disabled people.

The first section continues with an outline of the research methods used to address the three central research questions stated in the conclusion of Chapter 2, The Research Terrain. Data collection was conducted under an international comparative study mantle. The main method involved organisational case studies. The study gathered both quantitative and qualitative information from meso (organisational) level bodies. The research technique included the use of semi-structured interviews and an online survey that was distributed in Scotland and Norway.

The second section, Epistemology, addresses the epistemological stance of this study. This section sets out the approach to the question:

**2. What needs to be known?**

This focusses on pre-existing theories I, as the researcher, engaged with before conducting fieldwork and the ways in which this knowledge shaped the generation of theory during data analysis. One of the main contributory features of this study is an epistemological advocation of a social theory of impairment alongside the social theory of disability (Abberley, 1987; Godley, 2011). This approach is encompassed by the social relational model of disability (Thomas, 1999).

The third section, Ontology, examines the question:

**3. How are the objects of the analysis/research (e.g. data), to be understood?**

A reflective research practice enabled transparency of my motivations behind the study, potential issues encountered surrounding personal identity and researcher bias. The use of first person throughout this chapter also illustrates the subjective bonds between me as a researcher and the topic under scrutiny.

The fourth section, Sampling Strategy, highlights my epistemological, ontological and methodological postulations. For instance, where these shaped understandings of validity, reliability and replicability. The next section, Data Analysis, explores the adaptive theory coding approach towards data analysis; while the final section, Ethical Considerations, outlines the ethical considerations throughout this study. This chapter closes with a summary of the key contributions of the adaptive theory methodological approach underpinning the field work for this study.

## 3.1 Research Methods

My methodological approach required the selection of research methods that would uncover the explanations desired in order to investigate the three central research questions at structural, organisational and agency levels of analysis. A concurrent strategy (Curwin and Slater, 1991) was adopted to gather quantitative and qualitative data. This section sets out Layder's adaptive theory approach that guided the research process before an examination of each research method and the rationale behind their used. The study carried out organisational case studies of the Glasgow Centre for Inclusive Living in Scotland and Uloba in Norway. The organisational case studies utilised semi-structured interviews to yield qualitative, comparative, in-depth explorations of complex meanings, opinions or social practices; whilst an online survey (see Appendix XII) distributed to organisations in the disability fields in both countries produced qualitative data from which to judge relevance or corroborate patterns within themes (Bryman, 2004; Creswell, 2009; Silverman, 2006; Yin, 2009).

The methodological approach of this study was shaped by adaptive theory (Layder, 1998). According to Layder (1998), social inquiry conducted through a general theory, middle-range theory or grounded theory contains various inherent drawbacks. For example, he asserted that general theory can negate subjectivity and, along with middle-range theory (Maynard and Purvis, 1995), prioritises theory testing; whilst grounded theory, in contrast, lacks structural analysis and does not draw upon empiricist conceptualisations. Table 3.1 (Layder, 1998: p.10) demonstrates the polarities of theory testing and theory generating approaches.

The emergence of adaptive theory has its origins in grounded theory (Layder, 1982). There are two distinct ideological strands to grounded theory; anti-formalism, where meanings hold reality for symbolic interactionists, and qualified formalism (see for example, Glaser and Strauss, 1967), where empiricist validity measures were introduced (Fernandez, 2012). However, adaptive theory emphasises commonalities amongst grounded theorists. These include the rejection of dominant grand theories such as Parsonism (1951), which can block development of generating theory and seek micro (agency level)/macro (national policy level) data analysis.

**Table 3.1 Dimensions of Theorizing in Social Research**

| Theory focus | Empirical focus |
|---|---|
| Theory-testing | Theory-generating |
| Formal theory | Substantive theory |
| Epistemological | Ontological |
| Sensitizing concepts | Explanatory frameworks of concepts |
| Continuous part of research | Discrete part of research |

Source: Layder (1998: p.10)

The main method for this study was the organisational case study. I chose the Glasgow Centre for Inclusive Living (one of two Centres for Inclusive Living in Scotland) and Uloba (Norway's sole Centre for Independent Living) as extreme organisational case studies (Flyvbjerg, 2006). Both organisations were unique in their countries as user led organisations: run by disabled people for disabled people. They shared an overall goal to promote independent living for disabled people and adopted user led governance structures and accountability procedures to their membership (Barnes, 2003).

Centres for Inclusive Living are numerically scarce in Scotland and Norway, which explained, for example, why regional level comparisons within the same country

would not have been possible. The choice of Norway as a comparator reflected a desire to look at the impact of different factors, such as a contrasting welfare regime, with divergent policies around independent living underpinned by an alternative cultural value system. These additional dimensions contributed towards the overall understanding of the topic, analysis and theory-generating. For instance, inferences that arose from two liberal countries may be attributed to that sole regime context, without a viable transfer of concepts or mechanisms to other countries or contrasting settings.

Flyvbjerg (2006) discussed misconceptions about common misunderstandings involving the use of case studies. These are:

a) Theoretical knowledge is more valuable than practical knowledge;

b) One cannot generalise from a single case; therefore, the single-case study cannot contribute to scientific development;

c) The case study is most useful for generating hypotheses, whereas other methods are more suitable for hypotheses testing and theory building;

d) The case study contains a bias toward verification; and

e) It is often difficult to summarise specific case studies.

However, I chose the case study method for its strength, as acknowledged by Flyvbjerg (2006), of having the ability to detect 'black swans'. This is where falsification is one of the most rigorous mechanisms through which a researcher is able to carry out in-depth and contextual explorations to examine scientific propositions. A case of invalidity can lead to revision or rejection of postulations. Hantrais (2004) echoes this by stating that close-up investigations of social phenomenon can reveal differences attributable to variables such as geographical location, age or access to social entitlements. These, as Hantrais (2004: p.271) explained,

*"...may not be apparent when aggregated national level data are being compared from a distance. The close-up view allows identification of subnational variations that may result in greater similarities being found across countries than within them. Although most social policies are framed at national level, they are often implemented at local level, providing scope for regional disparities..."*

The organisational case studies of GCIL and Uloba provided an opportunity to gather data using different methods. Each method illuminated specific contours of the three central research questions. This study attempted to avoid oppositional polarisation of quantitative versus qualitative methods as depicted by Bryman's table (see Table 3.2), and instead sought to combine an agency/structural data collection approach.

**Table 3.2 Fundamental Differences between Quantitative and Qualitative Research Strategies**

| Orientation | Research Strategy | |
| --- | --- | --- |
| | Quantitative | Qualitative |
| Principal orientation to the role of theory in relation to research | Deductive; testing of theory | Inductive; generation of theory |
| Epistemological | Natural science model, in particular, positivism | Interpretivism |
| Ontological | Objectivism | Constructionism |

Source: Bryman (2008: p.22)

The first research method used throughout this study was semi-structured interviews. These were carried out with nine employees from the Glasgow Centre for Inclusive Living, eight Uloba employees and four service users/co-owners in each country. Simons (2009) noted that in-depth interviewing has four key purposes: to document views or experiences of a topic; to promote active engagement and learning for interviewer and interviewee, especially in identification and analysis of issues; to pursue themes in a flexible manner that deepens responses; and to uncover unobservable feelings or events. This is what Oakley (1981) termed interactional interviewing, which aimed to establish an

equitable relationship between myself, as interviewer, and the interviewees, by creating opportunities for active dialogue.

This emphasised the role of participants as subjective human beings who need to be served by the research. In doing so, Bertaux and Bertaux-Wiame (1981) outlined that my role as the researcher was to listen beyond the words of narration and engage with representations of participants' social culture. They argued that theoretical abstraction can also be checked through stories.

The open-ended interview schedules (see Appendices VIII-X) used in this study enabled participants to share their biography that told the history of their life project. This could support statistics, deliver greater impact of the overall findings with these individual stories and illustrate the diversity of experiences (Priestley, 2001; Shah and Priestley 2011; Wengraf, 2000). Open-ended interview schedules helped inform participants of overarching themes and acted as a support mechanism for novice researchers, like myself. As constructivist, grounded theorist Charmaz (2006: p.18) described:

> *"…an open-ended interview guide to explore a topic is hardly of the same order as imposing received codes on collected data. Simply thinking through how to word open-ended questions helps novices to avoid blurting out loaded questions and to avert forcing responses into narrow categories. Researchers inattention to methods of data collection results in forcing data in unwitting ways and likely is repeated over and over."*

The second method deployed was an online survey of disability related organisations in Scotland and Norway. This method is normally associated with large-scale quantitative research that seeks generalisation across a target population. However, surveys can take different forms (Curwin and Slater, 1991). My online survey was qualitative in nature. It looked to infer trends and patterns amongst disability related organisations' attitudes, opinions or experiences towards access to independent living for disabled people in their country, as well as their relationships, if any, with the organisational case studies. The survey design therefore reflected the type of information sought (Creswell, 2009; Gilbert,

2008; Seale, 2004); questions ranged from closed (yes/no) to scale ratings and open-ended blank text boxes, which encouraged as many qualitative responses as possible (see Appendix XII).

The Scotland survey received thirty responses from disability related organisations, whilst the survey in Norway received twenty responses. An overview of basic characteristics of survey participants showed that the Scotland survey had eight males and twenty-two females, with twenty participants who chose anonymity. The most common age range was 45 to 54 years old, and the most cited job role was departmental director. The Norway survey had nine males and eleven females, with ten participants who chose anonymity. The most common age range was slightly younger, 35 to 44 years old, and the most common job role was advisor.

The survey instrument chosen was Bristol Online Surveys (Bristol Online Surveys, 2015). This was preferred over alternatives since it was free to use through the University of Stirling's subscription, it provided ease of data export to analytical tools such as Excel or SPSS, it conducted cross-tabulations and had basic functions that I found accessible with speech software. My personal learning assistant performed more advanced tasks, including the creation of the survey format. For distribution in Norway, English and Norwegian surveys were supplied and research participants were invited to respond in English or Norwegian. A Norwegian translator assisted with converting the questions into Norwegian, and any Norwegian responses into English.

According to Layder (1998), adaptive theory encourages this multi-strategy approach. He explained that there are advantages during triangulation of many sources of data and/or methodological and analytic strategies for the research project. A key strength lies in the aid of theory-generation through increasing density, and the validity of theoretical ideas and concepts that emerge from data collection and analysis. Layder identified two mechanisms that underpin this process. Firstly:

*"A multi-strategy approach produces a multi-perspectival 'overview' which increases the potential for more and more robust theoretical ideas", whilst "...synergy which is conducive to re-orderings and re-interpretations of the findings which may lead to theoretical breakthroughs."* (Layder, 1998: p.21).

However, a note of caution is that triangulation does not equate with guaranteed validity. Each research method possesses weaknesses as well as strengths towards data collection (Bell, 2005; Denzin, 1997; Mason, 2002). With any social inquiry, as Popkewitz and Brennan (1997) pointed out, the most that can be expected are glimpses of potential truths.

This research design was conducted under an overarching international comparative research mantle. Antal et al. (1987) remarked that comparative research resembles the closest approximation to the controlled laboratory experiment for social scientists. For Scotland and Norway, with the organisational case studies under scrutiny, key divergences were reflected, namely contrasting housing systems (the original focus of the study) and welfare typologies (Esping-Andersen, 1990). They showed convergence of other variables, such as population sizes: approximately 5.2 million and 5.0 million (Scottish Government, 2012; Statistics Norway, 2012), and both have experienced being governed by coalition governments.

Kohn (1987) asserted that the central goal is to provide explanation at a level between what is true for all societies and what is true of one society at a specific point in time and space. A second goal is to fill in gaps in knowledge for domestic and foreign policy (Dogan, 2002; Dolowitz and Marsh, 2000; Dolowitz et al., 2000). Roy Macridis concluded that this field was:

*"essentially non-comparative ... essentially descriptive ... essentially parochial ... essentially static ... and essentially monographic"* (Macridis, 1955: p.7-12).

However, other authors have gone on to endorse comparative research. For instance, Heidenheimer et al. (1983) recognised that it acts as a busy crossroads

for multiple disciplines and that these origins have fostered many beneficial collaborations and learning opportunities. As they outlined (1983: p.8) it:

> *"...provides a setting where political scientists, sociologists, historians, and economists are learning from one another."*

Although comparative research methodologies mirror non-comparative counterparts, a key characteristic is that the scope and scale demand greater complexities (Berthoin et al., 1996).

This international comparative research endeavoured to define contextual comparators using comparative research typologies. A famous example of this classification process is Aristotle's six forms of rule: monarchy, aristocracy, polity, tyranny, oligarchy and democracy (Hague et al., 1992). These were based upon the combination of their form of rule (good or corrupt) and the number of those who rule (one, few or many). The main task of typology building around the primary focus at the beginning of comparative research is to help the researcher affirm direction and guide the prioritisation in a multi-perspective elaboration (Layder, 1982). I drew upon Esping-Andersen's definitions of:

1. **Decommodification:** the degree to which social policy makes individuals independent of the market.

2. **Stratification:** the degree to which the welfare state differentiates between different groups (e.g. according to occupational status). The opposite of stratification is solidarity, whereby the welfare state offers the same benefits and services to the whole population.

## 3.2 Epistemology

Thomas' (1999) social relational model of disability underpins the theoretical framework applied in this doctoral research. The emphasis is placed upon uncovering knowledge, experiences and perspectives from both a structural level and an agency level within society. Layder's adaptive theory (see Figure 3.1) sets out a research process that operationalizes the social relational model in practice.

**Figure 3.1 Layder's Research Process**



| | *Elements of the research process* |
|---|---|

Choice of topic/problem

Theoretical deliberations

Data analysis and theorizing

Methods and techniques

Sampling, coding and memos
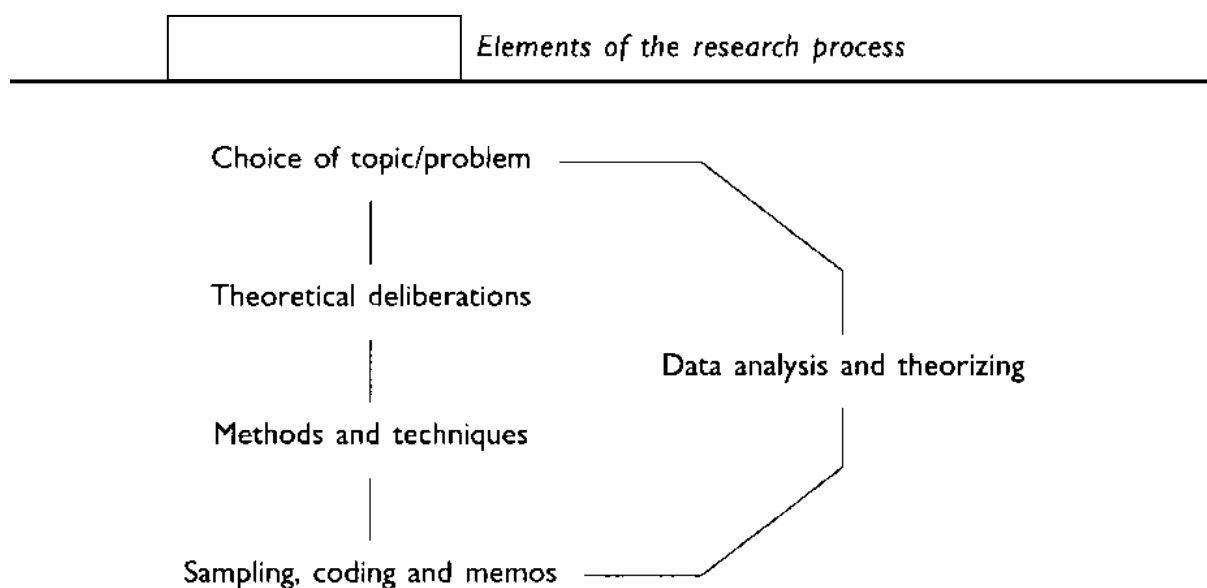
Source: Layder (1998)

The first phase is choosing a topic. Here, my biography played an important motivation: lived experience of disablement in Scotland with an observation that certain practices or policies facilitate or impede access to independent living for disabled people. Layder (1998) points out that researchers bring to any study their value systems or pre-conceptions. As he asserted (1998: p.1):

> *"Adaptive theory endeavours to combine the use of pre-existing theory and theory generated from data analysis in the formulation and actual conduct of empirical research."*

I recognised that I did not come to the research process with a value-free blank sheet (Blaxter 2007; Burgess 1995; Delamont 2003; Hammersley 1997; Letherby 2003). This study will be coloured by my personal and cultural value basis, as well as my prior knowledge of the topic. Layder (1998) advocated a pre-field work literature review in order to gain an insight of the key general theories and conceptual postulations in the area of investigation. This, as was evident in my case, acts to stimulate a researcher's creativity, which is necessary for generating theory (Charmaz, 2006; Goulding, 1999; Nielsen, 1990). For instance, my academic background stems from housing studies and I was aware that the recent

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social gaze (Bauld et al., 2005; Judge and Bauld, 2006; Morley, 1999) in Scotland was shifting towards issues surrounding the shortage of affordable and accessible housing (Scottish Government, 2011).

Thus, my initial inspiration for the research was to demonstrate that accessible housing was the most important area to facilitate independent living. However, my engagement with the literature around the concept of independent living highlighted that disability studies' academics, such as French and Swain (2008), were calling for a holistic perspective. People's lives, they argued, cannot be divided into neat silos. Therefore, access to independent living needs to recognise the interconnections and impact upon all areas of life. Consequently, my research focus broadened. My overall research question emerged as:

**To what extent do the organisational governance structures in the Glasgow Centre for Inclusive Living and Uloba facilitate or impede disabled people's access to independent living?**

This provided an open-ended exploration of the various areas of independent living and research participants' perceptions around impediments or facilitators. The research aims were to uncover the lived experiences of disablement in Scotland and Norway, with particular reference to independent living; examine the interconnections between citizenship, disability and areas of independent living; and identify whether the organisational case studies highlighted specific forms of governance that enhance disabled people's access to independent living. These aims addressed gaps in knowledge illuminated during my theory elaboration (Layder, 1998). I began by consulting different general theories within disability studies. This assisted in identifying my epistemological and ontological stance, which shaped what Miles and Huberman (1994) referred to as the conceptual tool box; in other words, the conceptual frameworks that I would apply to the data collection and analysis. I started off with a narrow knowledge base, which split into diverging streams of thought as I pursued various avenues of inquiry. Some themes were discontinued until the remainder eventually converged into a coherent epistemological and ontological approach (Simons, 2009).

For example, one of the key texts for disability studies was Oliver's (1990) "The Politics of Disablement". He presented the social model of disability, which since then has been criticised for privileging a materialist perspective that omitted individual impairment affects. Alternatively, post-modernist disability study writers, such as Corker (1998), are accused of failing to apply theory to practice (Oliver and Barnes, 2012). One of the key contributory features of this study was an epistemological stance that advocated social theory of impairment alongside social theory of disability (Abberley, 1987; Goodley, 2011).

Therefore, this study aligns most closely with Thomas' (1999) social relational model of disability. As outlined in the literature review in Chapter 2, the social relational model aims to bridge micro/macro levels of analysis of disability by combining external factors of disablement and individual psycho-social impairment affects. It also fitted with the overall adaptive theory approach throughout this study, as described by Layder:

> *"...adaptive theory focuses on the ties between agency and structure in social life and the connections between macro and micro levels of analysis."* (Layder, 1998: p.26).

## 3.3 Ontology

Ontology denotes what level of explanation is desired to answer the central research questions and who are considered as knowers of knowledge (May and Williams, 1998). For the former, I required macro (national country, in this research denotes Scotland and Norway), meso (organisational) and micro (individual) level explanations across the research questions. Governance analysis covers all of these strata in society. This emerged from the literature review and provided the means through which to examine the role of democracy in each organisational case study and their country.

I was able to gain insights from the research participants into ways lines were drawn between those deemed deserving/non-deserving of welfare assistance, resources and support for independent living (Kirkebæk and Simonsen, 2001). I placed at the heart of this study the sense of interconnection between structural

factors (e.g. policy measures, physical environment and the role of the voluntary sector) and agency factors (e.g. lived experiences of disablement, self-perception and degree of attitudinal acceptance from others).

Lowe (2004) supports such an institutional approach. As he explained, it focuses upon the provision differences and the decision-making outcomes within the public policy process, as well as giving cultural context and historical location. With the latter elements, this is referred to as historical institutionalism, which views the historical context as crucial for having shaped the current situation within politics and countries. This study's research questions demanded a meso level focus. Meso analysis, as outlined by Lowe (2004), contains two inter-related meanings. Firstly, it incorporates the organisations, networks and intergovernmental bodies that are the agency and structure of the policy process. Secondly, it describes the number of linking themes known as leitmotifs - themes binding different levels of analysis and that reoccur during data analysis.

Accordingly, Lowe continued that a meso level focus demands information that is best unearthed via qualitative data collection. Therefore, I applied governance (Bang, 2003) to organisational case studies and not at a national level. This reflected the depth of data sought during fieldwork, which was deep, contextual and detailed. It showed the decision-making apparatus the case study respondents utilised at macro (influencing national policy), meso (influencing partnership working with other disability organisations/service delivery agencies) and micro (the influence of a user led ethos) levels.

This study does not, for instance, place the governance focus at a country-parameter by comparing welfare typologies. The main theoretical model for welfare typologies was that by Esping-Andersen (1990). I decided to avoid looking at liberal, social-democratic and corporative systems, and instead concentrate upon uncovering deep, contextual information from organisational case studies within two countries. With more countries, it could be easy to negate or miss important meso level and micro level analysis in particular (Hantrais, 2004).

One of the other main obstacles to such an approach was also my inability to access research participants from the Norwegian State. Although a counterpart in Scotland took part, it meant my macro-analysis was thinner than originally desired. The data also indicated connections for independent living at a European level. A country-governance focus, therefore, could have also benefited from explorations around the involvement of Scotland's and Norway's Disabled People's Movements within the European independent living policy-making arena.

The second aspect for consideration with this ontological approach was who I perceived as knowers of knowledge for the study. I was guided by the features of emancipatory research as defined by Barnes (2003). He summarised that the emancipatory research process must cover accountability of the researcher, emphasise the role of the social model of disability, justify the choice of methods, ensure empowerment of research participants and disseminate research findings and outcomes. However, this study cannot be described as fully emancipatory in nature. It was based upon the principles of equal human rights (Shakespeare, 1998b) and the generating of theory from the study to contribute towards greater awareness of disabled people's access needs around their independent living, which might inform future social change (Sandvin, 2003).

The Disabled People's Movement identified the following principles for emancipatory research: equal relationships between researchers and research participants; research that aims to support the empowerment of service users; and a study that is committed to making broader political, social and economic change, in line with the rights of service users (Mercer, 2002; Oliver 1996). Although I support all of these intentions, I had to recognise that my thesis harboured constraints. For example, co-production is the most intensive approach to ensure that the needs and desires of users are reflected by research.  Co-production was not adopted during this doctoral study due to time constraints, resource restraints (finances) and the expectation that I, as the researcher, demonstrate the ability to lead and execute the research under the ESRC 1+3 PhD programme.

I was well aware that the full extent of this doctoral study would be impossible to gauge or realise since this would occur after submission. For example, I have

planned publications and future conference presentations as part of the dissemination phase. From the outset, I also knew that this study would not make any direct differences or improvements to research participants' lives and their access to independent living in neither Scotland nor Norway. Ultimately, I made the decisions around the research design which would not have been the case under, for example, a co-production approach. I determined the priorities for inquiry, I conducted the interpretation of the data, I assembled the data findings in a final thesis and I produced/disseminated conference presentations or articles with my name attached to them (Shakespeare, 1996b).

Moreover, throughout this three-year doctoral study, my resources in terms of time and research finances were very limited. An alternative approach, for example, that adopted a co-production research design may not have been feasible or would have entailed the omission of particular analytical elements. International comparative research is, as noted in the literature review, itself time-consuming and expensive to carry out. Therefore, co-production would have worked best using one country, and thus the comparative research design feature would have been dropped. On a positive note though, I was able to address the aspects of equal power relations between myself, as the researcher, and research participants, as well as the use of some empowerment techniques. Reflexivity throughout made me aware of power relations and my accountability as researcher.

It was necessary during the initial focus of social inquiry to map the central decision-making processes in relation to policy-making approaches in both countries. The Norwegian Anti-Discrimination Act (2009), for instance, illustrated the country's governmental approach towards disability. This fed into the evaluative phase, whereby policy analysis, alongside individual service user/co-owner accounts, provided context and clarity of themes such as legal conditionality or entitlement. Furthermore, power was at the heart of reflections around my role as a self-identified disabled researcher with a visual impairment. Disability studies have highlighted that mainstream research often fails to incorporate or reflect the needs of, or respect the inclusion of, disabled people (MacLachlan and Swartz,

2009; Oliver, 1992). For instance, Bogdan (2001) explained that in the past science viewed disabled people as specimens to be tested, measured and categorised without recognition of their humanity, biography or feelings.

I was also conscious that these concerns were present amongst some research participants. For example, senior GCIL manager Leigh discussed their preference for disabled researchers investigating the lives of disabled people. However, for Leigh what was most important echoed Traustadottir's (2001) discussion of where there must be the assurance of validity, giving control to research participants over the data and checking about its use with research participants. The four main ways I gave control to the research participants were (i) by obtaining consent to conduct qualitative interviews; (ii) informing participants that the data would only be used for that study and not be absorbed into future projects' data analysis; (iii) by presenting interview transcripts to each participant to verify my account of the conversation/check out meanings (see Appendix VII); and (iv) the act of seeking/prioritising the voices of service users/co-owners on the topic.

As Watson (2002) has commented, reflexivity is an integral component of our sense of self and sense of others. Therefore, throughout the fieldwork I utilised techniques to plan for potential power imbalances, such as piloting to ensure neutral, comprehensible language, whilst employing active good listening skills during qualitative interviews helped to avoid potential leading questions or presumptions of participants' meanings (Ritchie and Lewis, 2003; Seale, 2004, 2007; Shakespeare, 1996b).

Additionally, reflective research demanded that I stay alert to potential researcher effects. During this study, personal characteristics such as being female, 29 years old (at time of the fieldwork), white, working class and having an Edinburgh accent and visual impairment will undoubtedly have impacted upon the data in different ways. It was difficult to identify where these researcher effects may have occurred, especially during the face-to-face qualitative interviews. I was unaware, for instance, what a participant may not be disclosing based upon their perceptions of me as the researcher. Coffey (1999), Gill and Maclean (2002) and Middleton

(1986) and have all highlighted the sense of powerlessness researchers can experience without any means to control others' perceptions of them.

## 3.4 Sampling Strategy

The sampling denotes the identification by the researcher of what type of, and how many, cases should be included within a research design (Landman, 2000). I selected sources that I determined would provide appropriate, reliable and valid information to aid the exploration of governance structures that facilitate or impede disabled people's access to independent living. Under an adaptive theory approach, Layder (1998: p.109) described that theory-generation is "best served through relevance to explore emerging categories, properties, hypotheses and integration of the theory".

The key research methods choice for this study was designed to focus upon international comparative organisational case studies of the Glasgow Centre for Inclusive Living in Scotland and Uloba in Norway. These were systematic, small sample case studies within single-nations (Mackie and Marsh, 1995). This provided what Yin (2009) referred to as embedded case studies, which enabled comparative, consistent opportunities for data collection. As Hantrais (2004: p.269) described:

> *"The smaller the number of countries included, the greater the contextual detail, and the easier it is to be consistent in specifying and applying concepts and in using qualitative evidence. Findings will differ depending on the mix of countries and the variables selected."*

Layder (1998) pointed out that using adaptive theory throughout a sampling strategy concentrates upon the contextual conditions of interactions. This examines the contextual conditions that give parameters for certain social interactions or outcomes to emerge. I needed to know the backgrounds, and there are two Centres for Inclusive Living in Scotland: the GCIL and the Lothian Centre. I chose the GCIL based upon the wide range of services that it offered for independent living. This gave the opportunity to examine insights of a holistic perspective towards independent living (services addressing all aspects of life and

not within silos) and to compare the significance of one particular service for service users against others (French and Swain, 2008).

Contrastingly, Uloba was the sole Centre for Independent Living in Norway. Its model revolved around the provision of personal assistance via a peer counselling approach. Other aspects of independent living, such as accessible housing information, were provided indirectly for co-owners (Solvang et al., 2003). My sampling strategy viewed GCIL and Uloba as extreme cases (see Table 3.3). They shared a unique characteristic as fully user led organisations run by disabled people for disabled people.

**Table 3.3 Strategies for the Selection of Samples and Cases**

| Type of Selection | Purpose |
|---|---|
| **A. Random selection** | To avoid systematic biases in the sample. The sample's size is decisive for generalization |
| 1. Random sample | To achieve a representative sample that allows for the entire population generalization |
| 2. Stratified sample | To generalise for specially selected subgroups within the population. |
| **B. Information-oriented selection** | To maximise the utility of information from small samples and single cases. Cases are selected on the basis of expectations about their information content. |
| 1. Extreme cases | To obtain information on unusual cases, which can be especially problematic or especially good in a more closely defined sense. |
| 2. Maximum variation cases | To obtain information about the significance of various circumstances for case process and outcome (e.g., three to four cases that are very different on one dimension: size, form of organisation, location, and budget). |
| 3. Critical cases | To achieve information that permits "If this is (not) valid for this case, then it applies to all (no) cases." |
| 4. Paradigmatic cases | To develop a metaphor or establish a school for the domain that the case concerns. |

Source: Flyvbjerg (2006: p.230)

At the commencement of the study, I identified three key experts in both countries from the field of disability studies and housing studies. They emerged from the

initial literature review as important commentators or representatives of particular bodies. They provided an insight into the context of each country and its organisational case study. Their views reflected key trends and debates. This was particularly important so that I did not pre-assume about certain issues surrounding independent living in Scotland. Additionally, in Norway, I recognised that I was an outsider without the cultural, social or political frames of reference to draw upon (Hantrais, 2004). Lowe (2004) highlights researcher ethnocentrism whereby during comparative studies, researchers need to avoid making potential judgements in relation to other countries based on their country of origin's institutional landscape and cultural setting.

The organisational case studies played an important gatekeeping role (Simons, 2009) during service user/co-owner selection. They provided contact details of potential participants who had expressed an interest in the research. To prevent any perceptions of coercion, GCIL and Uloba approached specific individuals on my behalf. Here lies the possibility that these people were chosen to portray certain perspectives or interpretations of the organisations, although, from the responses this was not obvious. Another consequence was that there lacked representation of participants with cognitive or sensory impairment, or from ethnic minority groups. Again, I received the impression from GCIL and Uloba that this was not a deliberate act.

Additionally, I approached disabled-led organisations' umbrella bodies, namely Inclusion Scotland and the Norwegian Federation of Organisations of Disabled People, the FFO, to circulate my online survey invitation (see Appendix IV - email survey invitation) to their members on my behalf. The purpose of this online survey was not to generalise within the wider population or make statistical correlations. Responses provided qualitative insights into the partnerships, opinions and connections other disability organisations had with the organisational case studies. However, I lacked control over who participated.

An issue that held potential contentions involved the decision of when to stop sampling. As Dey (1999) pointed out, it is a more complex decision than merely experiencing the saturation of themes. What I was looking for instead was enough

data to provide in-depth comparative analysis that highlighted patterns and conceptual constructions that led to theory-generation. It is difficult to accept where to stop with this model, especially given that independent living for disabled people touched upon a multitude of areas or aspects. As Dey has summed up (1999: p.170):

> "Therefore, a decision not to collect further data can be no more than a guess (albeit more or less well grounded) that such an investment is no longer worth the trouble given the likely (theoretical) reward. We certainly cannot predict accurately whether the very next round of data collection (or even a further trawl through our current dataset) might throw up something that suggests an important modification or even a new perspective."

Although a coherent research process was followed by establishing research instruments and protocols (see Appendices), replication of this study could pose challenges. For example, Kvale (1996) commented that studies lack comparable equal social phenomena to enable scientific replication. My subjectivity, even with a coherent research strategy, colours the research process, analysis and interpretation since qualitative data is not linear. I am aware, for example, that since fieldwork in 2012 GCIL has developed further services and projects, such as the Equalities Academy. This demonstrates Simon's (2009) point that case studies provide a snapshot and are specifically located in time and place. A salient example within this study arose with the recent changes towards welfare policies in Scotland. Many participants voiced concerns about these upcoming financial changes and the potential implications for their access to independent living. However, at the time of the completion of this thesis new legislation, such as the Welfare Reform Act 2012, had come into force and the research participants may have altered their opinions.

## 3.5 Data Analysis

Data analysis for this study was coloured by my epistemological and ontological positions. This is demonstrated in my conceptual thinking around general and substantive theory, and highlights the role of subjectivity during data analysis with

alternative interpretations as possibilities. Under the adaptive theoretical approach, as Layder (1998) outlined, there were two key characteristics of the analysis process. The first was a continual flexible dialogue between theory emergence and theory generating; flexibility facilitated the pursuit of various strands of inquiry during data collection and data analysis. The second was theoretical pertinence. This involved an open-ended process that highlighted theoretical categories throughout qualitative interview transcripts and qualitative survey responses. For instance, the majority of participants touched upon all 12 Pillars of Independent Living (Spectrum, 2016). However, specific areas were mentioned more than others, or talked about in greater detail. The coding strategy uncovered saturation points whereby coding stopped when nothing new was revealed by the qualitative data. This left participants' priority themes as the most pertinent for analysis and discussion.

The process of coding during this study, according to theoretical pertinence, is illustrated below using the analytical schema presented by Layder (1998: p.57-58):

- **General and formal theories**: Holistic perspective of independent living (French and Swain, 2008); the ethic of care (Morris, 2006); social theory of impairment (Goodley, 2011); social relational model of disability (Thomas, 1999); governance (Bang, 2003); and citizenship (Beckett, 2006).

- **Substantive ideas**: Welfare typologies; occupational careers; self-identity; forms of peer support; organisational types; issues of inaccessibility for housing; and types of relationships connected with personal assistance.

Adaptive theory provided consistency towards coding of data, which helped ensure good quality research (Gibbs, 2008; Hinds et al., 1997). Audio recordings of interviews enabled a focus on interactions throughout conversations with participants and the ability to produce interview transcriptions (Yin, 2009). I had time to transcribe the Scotland qualitative information, but enlisted the assistance of a professional transcriber for the Norway interviews. I concluded that overall this would not affect data analysis. Each key expert, organisational case study

participant and service user/co-owner received their interview transcripts to check for any discrepancies or potential issues they would like omitted.

During analysis of these transcripts, I encountered technological inaccessibility issues. I looked at using NVIVO, a qualitative management program, beheld by some to be useful with high volumes of information, but as with SPSS for quantitative analysis, it turned out to be inaccessible for screen reading software; for instance, the speech software that I use, Jaws. Therefore, my strategy involved the operation of multiple Word documents and cutting and pasting across files, which according to Seale (2004) and Welsh (2002) enabled greater intimacy with, and immersion within, my data.

The online survey provided qualitative data for this study. As with the interview transcripts, the use of open-ended questions meant that I could apply theory pertinence during analysis. I had my general theories in mind and operated the cut and paste feature within a Word document to sort the responses into substantive themes. The survey data was held on a Bristol Online Survey account, which produced basic cross-tabulated information for the closed and scale rating style questions. I exported the survey information into Excel, for example, and coded numerically to find out the frequency of basic participant characteristics; for instance, the types of organisations that took part or how many respondents were also involved with the organisational case studies.

## 3.6 Ethical Considerations

This study adhered to formal guidelines and stipulations surrounding ethics. For instance, the University of Stirling Code of Good Research Practice was particularly relevant, as I was viewed as representing the institution during my investigation. It aimed to protect researchers, others affected by the research and the institution's reputation (University of Stirling, 2010). I also followed the Economic and Social Research Council's (2010) Research Ethical Framework. This applies to general ethical research practice and was based upon six principles: high quality research, informing stakeholders, confidentiality, freewill,

safety and independence. According to the Economic and Social Research Council's (2010) Research Ethics Framework principles:

I.  Ethical research is of a high quality. Thus, if a study is poorly designed, quite aside from the fact that it almost certainly would not receive financial support from the ESRC, it is unethical;

II.  Research staff and subjects must be informed fully about the purpose, methods, and intended possible uses of the research, what their participation entails, and what risks, if any, are involved;

III.  Confidentiality of information must be maintained, and anonymity of participants respected;

IV.  The involvement of research participants must be entirely voluntary;

V.  Harm to participants must be avoided;

VI.  The independence of research must be made clear, and any conflicts of interest or partiality must be explicit.

Thus, ethical considerations were undertaken at all phases of the research design. These included whether harm would come to participants or researcher, attainment of informed consent and avoidance of deception or invasion of privacy (Bryman, 2008; Creswell, 2009; Diener and Crandall, 1978). I was aware that social research itself was an ethical undertaking, especially when you are taking up other people's time, exploring personal lives containing potentially sensitive subjects, representing and interpreting other people's views and spending funding from a sponsor on comparative research (Ovretveit, 1998).

Kohri (1996) observed that cross-national research will come at a price, which applied to this study. The cost of fieldwork was high and was met by my student research fund, and supplemented by my teaching assistant work. Time, at certain phases, was a challenge. I adhered to a research timeline but during, for instance,

the transcribing of interviews, I needed to employ a professional transcriber to complete those for the Norway interviews. The research findings also raised further questions, such as are there any mechanisms that best foster peer support in contemporary times?

To ensure safety of myself as researcher, I informed my supervisor of all movements, carried a mobile phone with emergency contact numbers, had a companion as a sighted-guide and chose public, but private locations. Research participants were informed as best as I could manage prior to their participation. The aim was to prevent harm to participants by placing them in control of their data. Firstly, the research information sheet (see Appendix I) was distributed to all potential participants; it made them aware that their views would be kept confidential, digitally recorded and anonymised within the thesis, and that the data would not be used for future analysis without their further consent. I sourced services for communicational needs, such as British Sign Language interpreters or Braille, which could be requested by participants (Lowes and Hulatt, 2005).

Before every qualitative interview or online response, I obtained informed consent. The procedure aimed to ensure ethical consideration of the participants' right to feel secure, supported and in control, and to have an awareness of the length of time involved and their right to withdraw at any time. Both telephone and face-to-face interviews had verbal consent granted by participants; this was recorded instead of signing a consent form, which ensured accessibility for me as a visually impaired researcher (avoiding the potential of muddling consent forms or losing them), and also accessibility for all research participants since some individuals may have required assistance with signing or reading. To begin the fieldwork, I contacted the chief executive/director of the organisational case studies for consent to conduct the research and approach employees. The following steps were then followed when approaching potential case study participants, services/co-owners and key experts:

I. Phone the potential participant to introduce myself and the study, answer any queries, gauge potential interest and, if possible, identify a suitable date, time and location for the interview;

II. Email appropriate invitations (Appendix II, Appendix III, Appendix IV and Appendix XI), general information sheet (Appendix I) with the appropriate interview schedule (see Appendix VIII, Appendix IX and Appendix X) and the consent, recording of data and anonymity sheet (see Appendix V);

III. Send confirmation follow up email containing the appropriate details of the session, such as time, date, location and duration. Re-iterate that participants can withdraw at any time and make sure to include my contact details.

IV. Applicable only to electronic survey: send reminder e-mail to potential participants two weeks before survey closed (after reminder e-mail Appendix VI).

A challenging area within this study's ethical considerations was anonymity. For instance, the case study's organisations were unique: the Glasgow Centre for Inclusive Living was one of two CILs in Scotland and Uloba was the sole Centre for Independent Living in Norway. Within these, there were a relatively small number of employees, which meant that there was potential, particularly around job titles, for colleagues to identify each other from the thesis. I was aware during the fieldwork that it was obvious to other employees whose office I was going into, and they would immediately guess who had agreed to take part. Also the service users/co-owners were suggested by these organisations. This gave them knowledge of who the potential participants were. Although I anonymised all responses from the semi-structured interviews and surveys under pseudonyms (see Table 3.4), a blanket anonymity approach may not be effective as participants could be potentially identified due to their unique job roles. Research participants were given the opportunity to comment upon their interview transcripts and this sought to prevent the harm of participants during the presentation of the findings.

No situations arose whereby participants expressed views that contradicted the objectives or principles of their organisational case study.

**Table 3.4 Pseudonyms for Research Participants**

| Role | Pseudonyms |
|------|------------|
| GCIL services users | Pip; Alex; Ali; Jessie |
| Scotland key experts | Angel; Armani; Reese |
| GCIL case study | Leigh; Jamie; Casey; Kim; Sandy; Chris; Danny; Joe; Sam |
| Uloba co-owners | Skylar; Tayte; Asle; Per |
| Uloba case study | Bronnil; Skule; Espen; Aren; Britt; Kris; Kristian; Kirby |
| Norway key experts | Audny; Jensen; Gisli |

Note: Skylar, Skule and Aren are also Uloba regional leaders

Source: Author

Another area for ethical consideration was the dissemination phase. Linking back to the concept of an interactive, two-way process of interviewing (Oakley, 1981), a crucial aspect is to ensure that the research is meaningful and useful for the research participants, and not carried out just for the sake of accumulating more knowledge (Shah and Priestley, 2011). As mentioned earlier, I have already drawn upon the findings while participating, for example, at the Housing Studies Association, European Network for Housing Research, Lancaster University Disability and Urban Design conferences. I know that this mainly benefits me as the researcher, since it develops my future career opportunities within social research.

## 3.7 Conclusion

The research process for this international comparative study has been outlined in this chapter. The study's three central research questions were presented in the preceding chapter, the literature review. These were:

1. What practices or policies facilitate or impede disabled people's access to independent living?

2. In what ways do the governance structures of Centres for Inclusive Living enhance disabled people's access to independent living within societies?

3. Does the nature of self-identification affect disabled people's experiences of, and access to, independent living?

The aim of this chapter was to explain the choice of methods used to obtain the necessary data. In doing so, the methodological approach developed three underlying research aims that corresponded with each research question: to examine the interconnections between citizenship, disability and areas of independent living; to identify whether the organisational case studies highlighted specific forms of governance that enhance disabled people's access to independent living; and to uncover the lived experiences of disablement in Scotland and Norway, with particular reference to independent living.

Overall, my epistemological, ontological and methodological approaches shaped the sampling strategy, measurements of validity, reliability and replicability, as well as the study's data analysis and ethical considerations. My methodological approach towards the research questions involved the exploration of structural and agency explanations. A concurrent strategy reflected the type of information I desired. The research design focused upon organisational case studies of the Glasgow Centre for Inclusive Living in Scotland and Uloba in Norway. Additionally, the other methods utilised were semi-structured interviews to yield qualitative, comparative, in-depth explorations of complex meanings, opinions or social practices; key experts provided qualitative context on debates in their countries (Hantrais, 2004; Hantrais and Mangen, 1996); whilst an online survey produced qualitative data from which to judge relevance and the corroboration of patterns (Bryman, 2004; Creswell, 2009; Yin, 2009).

Triangulation of concurrent methods fitted the adaptive theory approach by providing insights at macro, meso and micro levels of analysis. It also enabled emphasis of the strengths of the overall research strategy, comparative research and the three research methods. This helped counteract inherent weaknesses within each instrument too (Bell, 2005; Denzin, 1997; Mason, 2002).

The literature review in Chapter 2 highlighted the interconnections between the concepts of independent living, citizenship and governance. Two theoretical frameworks were identified to provide macro, meso and micro analysis of disablement. Thomas' (1999) social relational model (structure/agency perspective) was integrated with Lowe's (2004) discussion of meso level governance analysis. Emphasis was placed upon the examination of organisational meso level qualitative data that would uncover relationships across the other tiers of society.

During my sampling strategy, I selected sources that I determined would provide appropriate, reliable and valid information to aid the exploration of governance structures that facilitate or impede disabled people's access to independent living. The organisational case studies of GCIL and Uloba provided insights into the ways that policies are operationalised into practice and experienced by users (Murray, 2006). In order to gain an in-depth understanding of the lived experiences of disablement in Scotland, and the interconnections between the organisational case studies and the general policy-making arena, I envisaged GCIL service users and Uloba co-owners to be illustrative of this knowledge.

Layder (1998) pointed out that investigation of a topic should be viewed as a flexible continuum, whereby pre-existing general theory inspires the data analysis, while data analysis can demand pursuit of alternative strands of general theory as well as generating theory. This worked well, in that I began the fieldwork with an overview of the different areas of independent living for disabled people in Scotland and Norway, but stayed alert to the priorities of the research participants. Consequently, accessible housing and personal assistance emerged as the most frequent aspects of discussions. I was able to look at these in more depth after the

completion of the fieldwork, to examine key theories or studies to help critically analyse the data.

Adaptive theory highlighted two key characteristics of data analysis applied in this study: a continual flexible dialogue between theory emergence and theory generating, and theoretical pertinence. The former encourages fluidity between theory emergence and generating theory. The latter adopts a data coding strategy that was open-ended. The coding strategy uncovered saturation points whereby coding stopped when nothing new was revealed by the qualitative data.

At every stage of the study, I have tried to be alert to ethical considerations surrounding participants and myself, as the researcher. Some of the key issues I encountered included respecting confidentiality, anonymity, public yet private locations, security measures and my obligation to disseminate the findings in order to produce positive outcomes from the study. Although not strictly in adherence with emancipatory research stipulations, this thesis tried to produce a meaningful investigation for all involved; it may have benefited those who took part by simply exploring the issues, or it might stimulate future co-production social research.

The following three chapters present, discuss and analyse the data collated during the fieldwork. Peer support, accessible housing and personal assistance emerged as priorities for research participants, and demonstrated interconnections that bind citizenship frameworks to the independent living ethos and disabled people's ability to access/control resources in Scotland and Norway. These chapters present findings from the data, uncovered in response to the research aims. Chapter 7, Future Facilitation for Independent Living, then goes on to propose an overarching conceptual framework to strengthen the governance structures of meso level organisations to facilitate disabled people's access to independent living in the future.

# Chapter 4. Peer Support

## 4.0 Introduction

The literature review and methodology chapters set the scene for this research and presented the central research questions, underpinned by the aims to:

- uncover the lived experiences of disablement in Scotland and Norway with particular reference to independent living;

- examine the interconnections between citizenship, disability and areas of independent living; and

- identify whether the organisational case studies highlight specific forms of governance that enhance disabled people's access to independent living.

The following three chapters present the results from this research. Narratives from the research participants identified three core themes: peer support, accessible housing and personal assistance. All three areas are components of the 12 Pillars of Independent Living (Spectrum, 2016). This chapter focuses upon the first theme, peer support.  Davidson et al. (2006: p.443) define peer support as:

> *"the belief that people who have faced, endured and overcome adversity can offer useful support, encouragement, hope and perhaps mentorship to others facing similar situations."*

The adoption of the social relational model of disability (Thomas, 1999) enabled an exploration of micro (agency lived experiences), meso (organisational) and macro (national decision-making) level explanations of peer support expressed by the research participants.

This chapter is divided in to four sections.  The first section, Micro Narratives of Peer Support, provides the discussion on lived experiences of peer support and the ways this shapes individual identities.  The second section, Meso Narratives of Peer Support outlines the construction of the organisational case studies, GCIL

and Uloba, mainly through collective peer support among disabled people at a meso level. Participants describe the implementation of the independent living ethos (Hunt, 2001) into practice, as well as the relationships with other disability related organisations.

The third section, Macro Narratives of Peer Support, presents the narratives of peer support at a macro level. In particular, this section draws attention to the ability of CILs to engage with national policy-making in Scotland and Norway.  The final section, Significant Findings for Peer Support provides an overview of the key peer support facilitators for disabled people highlighted throughout the micro, meso and macro narratives.  The chapter closes with an examination of the extent to which the data around peer support provides insight into the overall research questions.

## 4.1 Micro Narratives of Peer Support

The focus of the research was on organisational case studies of GCIL and Uloba. As Lowe (2004) and Radcliffe (1999) have pointed out, meso level analysis provides a useful technique through which to uncover micro and macro level explanations.  For example, the majority of case study participants (GCIL service users and Uloba co-owners) reflected upon their lived experiences of disablement and the interconnections with macro policy and micro practices.

### *4.1.1 A Shared Frame of Reference*

Micro level narratives of peer support uncovered that peer support leads to the development of a shared frame of reference for the majority of research participants in both countries.  Research participants outlined a two-fold experience of a shared frame of reference; on the one hand, as an individual journey towards the acceptance of the disabled self and, on the other hand, in the development of a sense of connection or belonging with other disabled people.  A shared frame of reference has been explored by authors such as Stanley (1999), who described that a sense of knowing can have epistemological, ontological and methodological ramifications. The research participants in this study discussed how peer support formed a linchpin of the ethos of the Independent Living Movement, instilled a shared frame of reference to shape individual identities, increased individual

understanding of the diversity of needs among disabled people as a group and heightened awareness of disability theory.

From its inception in the USA, the ethos of independent living spread across Europe due to a shared frame of reference among disabled people (Hunt, 2001). Many GCIL and Uloba participants highlighted how this gave people an awareness of disablement and the ability to engage with peer support. For example, GCIL and Uloba value their disabled employees' past or present involvement with the Independent Living Movement. They felt this helped to develop a shared frame of reference with potential new GCIL service users or Uloba co-owners, helped to construct a firm sense of self and provided a foundation for delivering person-centred advice. Certain positions, such as inclusive living advisors in GCIL and regional councillors in Uloba, were ring-fenced for these particular traits.

At an agency level, research participants highlighted that a shared frame of reference can take time to form and help towards the construction of the disabled self. For many of the research participants the first experience of peer support was in institutional settings, such as rehabilitation centres, which were often impairment specific or specialist services, such as units within mainstream educational institutions. For example, in Scotland, Leigh (GCIL senior manager) recounted their experience of acquiring a spinal injury during the 1970s. Leigh described their recovery in a spinal specialist hospital, Stoke Mandeville (no longer in operation), and how peer support developed as an important strategy towards the attainment of independent living for the patients in the ward. Leigh outlined that:

> **Leigh:** *"You got big places like Stoke Mandeville, where they've got big wards with dozens, if not hundreds, of people with spinal injuries, all kind of lumped together and trying to manage and get along together, so it was very early peer support, if you can imagine. It was a very macho environment, it was a very male kind of environment and you know, still is in some hospitals, and it was all about people, disabled people challenging each other to sort it all out and move on."*

Similar narratives were present amongst participants in Norway. Disabled case study interviewees and Uloba co-owners reported that they established relationships with Uloba members, or heard of Uloba through rehabilitation facilities. For example, Kristian (Uloba senior manager) recalled gaining guidance from Kris (Uloba founder) while staying at a rehabilitation facility. Kristian recounted their feeling of awe at Kris's energy to strive to access autonomy over everyday life decisions and their confidence within what was a male dominated environment at that time, within the Norwegian Independent Living Movement.

Uloba co-owner, Tayte, highlighted that peer support can be a slow process to develop with individuals. Tayte reflected upon their role as an Uloba regional work leader where it is necessary to show sensitivity and commit time. As Tayte remarked:

> **Tayte:** *"It depends on who's around them so there's a few challenges there before they acknowledge. They have to grieve, feel the loss themselves and then you have to let them take things in their own time. You can't just go in and say things are going to be fine and this is the way things are. You know, they can help and stuff but they have to accept it. They don't see straightaway, a way out and we have to tell them that you can trust us."*

This corroborates findings from researchers such as Davidson et al. (1999) that have demonstrated how peer support can play a central role in enabling people with cognitive impairments to access independent living. Davidson et al. (1999) highlight that the use of role models is one technique for effective peer support. Many participants in this research also reported that peer support gave them a role model which helped them to form an individual sense of self and wellbeing as a disabled person. For instance, Kristian (Uloba senior manager) found Kris (Uloba founder) to be an inspirational influence on their personal development during physical recovery through, for example, sharing useful coping strategies. Kristian began working with Uloba as a work leader and progressed to their current position as senior manager, as well as instilling the confidence to challenge decision-making at a national level to campaign for policy change to enhance disabled people's access to independent living in Norway.

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### 4.1.2 A Sense of Community

The majority of participants in both countries commented that informal social interactions sparked further explorations into access to independent living. For example, word of mouth was the most common way that participants found out from friends or family about services run by GCIL or Uloba. GCIL service user, Jessie, remarked that mixing with peers provided reassurance that support would always be possible, no matter how severe an individual's impairment. Furthermore, living at home was seen to be a viable option, with institutional care not an inevitable outcome.

Additionally, an increased awareness surrounding the diversity of needs strongly emerged from the participants' lived experiences of peer support. Many outlined that networking with other disabled people brought to their attention broader disability issues and the many needs of individuals. This journey was illustrated via GCIL service user Jessie's account of becoming a GCIL board member. As a wheelchair user, Jessie became informed of perspectives of other impairment groups on a range of issues. People, Jessie explained, can focus primarily on their own impairment type and forget the needs of other impairment groups. Moreover, Uloba senior manager, Bronnil, also reflected that this reflexivity illuminated cross-group discrimination. As a self-identified gay individual, they recounted that their personal experiences of discrimination had heightened their awareness of similar practices towards disabled people. Therefore, being in the company of individuals encountering similar prejudicial barriers provided a secure social environment within which to explore self-expression. As Bronnil explained:

> **Bronnil:** *"Nobody really wants to identify with a discriminatory group. We all want to be looked upon as good people, we all want to be looked upon as fine people, we don't want to identify as a group who is looked down upon, and that is a big problem for the group of disabled people because maybe they are forced to identify as disabled, or as being a person with an impairment, but very reluctant to identify with these who are identify with those who are being looked down upon or those who are discriminating."*

### 4.1.3 The Role of Disability Theory

Micro level narratives from research participants uncovered discussions around the role of disability theory within the formation of individual identities and shaping a shared frame of reference with other disabled people. As noted in the literature review, the 1976 UPIAS document, Founding Principles of the Social Model of Disability became a touchstone foundational document for the Independent Living Movement in the UK, and the earliest attempt to develop the social model of disability. Generally, this study exposed that most research participants engaged with disability theory, often with reference to practical implications. Regardless of a person's theoretical stance, a common goal was to displace the dominant medical model of disability (Drake, 1999).

Most participants outlined that their awareness of disability theory came from interactions with peers. Senior GCIL manager, Chris, gave an account of their initial experience of mixing with peers. For instance, their account demonstrates the way in which theoretical explorations led to a deepening of their sense as a disabled person, highlighted the challenges faced by disabled people and introduced them to the social model of disability. Chris stated:

> **Chris:** *"Like many disabled people, when you start talking to other disabled people and start talking about the social model a wee light bulb goes on and you start to think, it's not my fault, there are other factors at play here regarding why I struggle with trains, or why I can't get on and off buses or why employers don't seem that keen to hire me. And you stop blaming yourself, and you start looking at the basic functional aspects of society in both the ways the built environment is designed and delivered, and also in terms of people's attitudes."*

Another senior GCIL manager, Joe, related their exploration of the gap between theory and practical application of the social model. For example, during discussions with placement employers, Joe outlined that they take the opportunity to reinforce non-discriminatory language, replacing 'people with disabilities' with 'disabled people'. Talk about an individual's access needs only arose when

appropriate, and instead Joe focused upon the skills or assets of the prospective trainee that would be beneficial for the potential host.

Disability studies, many commented, was still a relatively new field. The key experts in Scotland and Norway concurred that since Oliver's (1990) book there has followed further explorations into theoretical perspectives. This includes Thomas' social relational model (1999), which re-entered discussions around impairment effects into disability theoretical debates. Closely connected, Angel, a key expert based in Scotland, described their preference for a critical realist perspective:

> **Angel:** *"... you can't just black box the body and say it's got nothing at all to do with impairment. And I think that if you talk about disability and the social model, disability becomes the must status. It's solely about disability so issues around gender, around ethnicity, around age disappear and disability becomes the dominant characteristic, and there are problems with that. And, I think ironically for a very materialistic model, issues around social class are underplayed. You know, the key marker that helps disabled people manage their socio-economic status and that's become much unpacked in terms of disability studies."*

Furthermore, some participants noted that Scandinavian disability theorists are making an impact upon disability studies. For example, Scotland key expert Reese and Norway key expert Gisli highlighted the work by Söder. Söder contributed towards Scandinavian disability studies from the early days of disability studies as an academic discipline (see Söder, 1989 and 1990). Söder (1999) explores the insights that can be gained from labelling theory as well as the overall theoretical progression by disability studies in more recent times (Söder, 2009). Reese and Gisli pointed out that regular conferences, such as the Nordic Network on Disability Research and online forums have provided a recent informal platform from which writers in disability studies can share knowledge and skills around the world. Echoing the coordinated approach of independent living (French and Swain, 2008), interdisciplinary working was also viewed as providing a complementary and progressive strategy for the future of disability studies. Angel, a key expert based

in Scotland, asserted that there was a need to re-engage with previous sociological writing, particularly around construction of self and meaning. This included authors such as Barry and Elmes (1997) and Williams (1984).

In particular, postmodernist theorists Shakespeare (1998) and Corker (1998) have examined the role of language, discourse and culture within disability studies. Many research participants discussed the term disability culture. For instance, in both countries there have been established separatist deaf cultures. However, in Norway, Uloba founder Kris noted that this group is now legally recognised as a linguistic minority with rights to segregated education.

### 4.1.4. The Expression of the Disabled Self

Discussions around identity showed that the majority of participants who self-identified as disabled held a temporal quality towards this self-perception. In other words, their sense as a disabled-person became central when faced with discriminatory societal attitudes, practices or environmental obstructions. Post-modernist authors in disability studies, such as Shakespeare (2006) and Corker (1999), have argued that this demonstrates the flexible nature of self-perceptions and that identity is not constant. For example, Angel, a key expert based in Scotland, suggested that other personal signifiers such as being a husband or an academic would take precedence. For Angel, their state of being was much more than their impairment type.

Uloba founder and senior manager Kristian mirrored these sentiments. Often, Kristian explained, the notion of being a disabled person would be forgotten, especially within the inclusive environment of the Uloba premises. Occasionally, an inaccessible building hindered participation during social gatherings at weekends and this highlighted to Kristian that macro, structural barriers still exist that hinder access to independent living, and consequently she became a disabled person again. Recent treatment for cancer had also brought with it a heightened sense of disablement. Echoing Thomas' (1999) notion of impairment effect, Kristian's narrative illustrated the way that an individual needs to adjust everyday practices, such as how many hours of work they can perform based upon a daily assessment of fatigue or pain levels. At the time of interview, a daily assessment

of Kristian's fatigue or pain thresholds at the micro level informed Uloba's meso level employment processes. For example, Uloba enabled home working and flexible hours to support Kristian. Kristian explained that a close relationship with their manager was essential and this has developed through a positive rapport.

Kristian's account of impairment effects supports disability studies writers such as French (1994) and Michalko (1999 and 2002). French (1994) has pointed out the way that a person's nature of impairment determines whether an environmental obstacle or social practice is experienced as an impediment or facilitator. For example, she highlights that a kerb can be useful for visually impaired people to distinguish between a road and pavement, while creating a potential environmental barrier for wheelchair users, particularly if the kerb is high.

Similarly, Michalko (1999 and 2002) draws attention to the sighted-landscape of knowledge that surrounds everyday interactions and assumptions. For instance, a study by Magnusson and Karlsson (2008) analysed the body language of congenitally blind individuals against those who had acquired a visual impairment. The former lacked knowledge of social cues or a repertoire of gestures to reflect or emphasise verbal interaction, since they had been unable to learn from the visual presentations of others around them.

Six of thirty Scotland survey respondents responded that they were disabled, while fifteen of twenty indicated so in the Norwegian survey. Two Scotland respondents chose not to be anonymous; these were Inclusion Scotland's Policy and Engagement Officer and Capability Scotland's Senior Policy Advisor. Both were female and aged 35-44 years. Inclusion Scotland and Capability Scotland are prominent organisations in the disability field which support the ethos of independent living. This may show that the two participants who disclosed their disabled identity operate in a working environment that seeks to affirm the disabled identity.

The four anonymous participants, two males and two females, were in the higher age ranges of 45-54 and 65 plus. One was retired and the other three in employment within an impairment specific charity and housing related

organisations. Their positions were at chief executive or managerial levels. One participant did not disclose their impairment type, one was registered blind and the other two had long-term degenerative muscular/joint conditions.

A higher proportion of Norwegian participants who identified as disabled waived the opportunity to be anonymous. A similar trend was present in the Norway survey respondents. Seven Norwegian respondents who self-identified as disabled chose to be identifiable. Four were male, and three female. Their age range was evenly distributed and their roles varied from a self-employed manager to a trainee in the county council. The majority of the organisations cited were related to disability in some form. As with the Scotland counterparts, this may suggest that disability organisations in Norway are more likely to support the ethos of independent living and employees may therefore feel comfortable to affirm a disabled identity. The impairment types disclosed included visual impairments and epilepsy, with the majority of respondents having multiple physiological conditions. Moreover, eight participants who self-identified as disabled chose to be anonymous; three were male and five female, and they occupied the higher age ranges. All indicated that they were involved with disability related organisations, either as employees or as volunteers. Respondents shared that they had a variety of impairment types; these included a few participants with visual and hearing impairments and one with epilepsy.

The online survey respondent profiles show that age affected an individual's decision to disclose that they are a disabled person. For example, the anonymous group were within the older age brackets. The results from the online surveys did not aim to produce generalisations in relation to the wider population but instead to indicate patterns across participants' predominantly qualitative responses. For instance, older respondents would have experienced or witnessed the early emergence of the Independent Living Movement. As detailed by disability studies' authors, such as Campbell and Oliver (1996), Morris (1991) and Hunt (2001), it was a further twenty years after the UK Sex Discrimination Act (1975) before equivalent acts were introduced for disabled people. In the UK this was through

the Disability Discrimination Act (1995), and in the year 2000 user-controlled personal assistance was legally recognised in Norway.

This meant that disabled people encountered stigmatisation, especially prior to anti-discrimination acts in Scotland and Norway and many would likely choose, if possible, to conceal their impairments to avoid potential negative treatment. Contrastingly, responses from younger respondents, who openly self-identify as disabled, may indicate that growing up in an era with the social model of disability (Oliver, 1990) and de-institutionalisation policies could have empowered them to adopt an affirmative disabled identity (Means et al., 2003, Tøssebro et al., 1996). Morris (2005) discussed the tensions surrounding disclosure of impairment to obtain rights and entitlements. However, this may result in the disabled person's loss of personal privacy. The other difference was the level of contact their organisations had with GCIL. Anonymous respondents reported no contact, whereas those who were identifiable reported a lot. This suggests that the peer support gained through interactions with GCIL staff may also encourage or support the latter's affirmative stance.

Shakespeare (1998) suggests that one of the tensions around disability is a tendency for people to try to pigeonhole impairment types. However, an individual can possess impairment without experiencing disablement, especially if they have full access to all areas of life, and therefore live independently. This was supported by the survey data from both countries. Eight Scotland respondents and sixteen Norway respondents recorded that they had impairments, and in the Scotland survey two respondents who identified as non-disabled had impairments. In both cases, this was a form of visual impairment. However, two Norwegian respondents that identified as non-disabled ticked they had impairments. The types of impairments described were more varied; for example, being unable to walk, Spinal Muscular Atrophy and congenital or hereditary conditions.

Observations from the Scotland and Norway surveys raise potential avenues for further social enquiry. For instance, a Norwegian study conducted by Sandvin (2003) contrasted with the survey respondents in this research. This suggested that younger disabled people may have a tendency to internalise disablement at

an agency level, rather than focusing upon the structural, macro level barriers that impede their access to independent living. Born in the 1970s, this generation reflects the neo-liberal welfare framework that has come to dominate across Europe since the 1980s and places emphasis on the life project or the personalisation agenda for service delivery (Pearson et al., 2014).

Sandvin's (2003) study notes a lack of interest in collective, peer support actions and this would be a valuable insight to examine in order to understand younger disabled people's interactions with disabled peers in Scotland and Norway, and to what extent these enhance access to independent living. Due to the self-selection sample of GCIL service users and Uloba co-owners, this research explored lived experiences of disablement among a group predominantly aged in their 40s and 50s. This meant that a generational comparison as conducted by Sandvin was not possible, and views or experiences, particularly of younger disabled GCIL service users and Uloba co-owners, were not present.

### 4.1.5 Summary

At a micro level, the narratives from research participants discussed the ways in which peer support can act as a key ingredient around the formation of individual and collective identities. The majority of participants recounted that hospital or rehabilitation settings produced environments conducive for peer support. However, many such institutions or services have been closed down under the shift towards care in the community (Means et al., 2003), and there is a gap in knowledge around effective vehicles to foster peer support.

Participants also described that the development of an affirmative disabled identity (Corker, 1999) and a shared frame of reference with other disabled people can take a long time. As Keith (1996) pointed out, disabled people need to learn how to do disability on a daily basis. In other words, disabled people not only need to learn about their impairment and any techniques or equipment to facilitate mobility, they also need to learn strategies to cope with attitudinal, environmental, financial, political and communicational barriers (French and Swain, 2003).

Many of the organisational case study interviewees outlined that peer support, at a micro level, developed the ethos of independent living in Scotland and Norway. These narratives supported the description of Hunt (2001), who wrote about the spread of the independent living ethos from the USA across Europe. Central to the argument, disabled people defined independent living as autonomy over everyday life decisions, for some of which disabled individuals may require assistance (Shakespeare, 1996).

A shared frame of reference among disabled people arose through, as many interviewees recounted, peer interactions and discussions of disability theory. As the foundational document produced by UPIAS (1976) on the social model of disability demonstrates, the Independent Living Movement not only sought to tackle the practicalities of disabled people's access to independent living but also the societal value system towards disabled people as a group (Oliver, 1990). Research participants showed an awareness and understanding of disability theory and reported, in some cases, that in conjunction with peer support, an individual's appreciation of the diversity of needs highlighted common goals between different impairment groups. Authors such as Morris (1992) and Hillier (1993), for example, have asserted that the Independent Living Movement must avoid a wheelchair user-centric perspective. The following section will go on to explore the ways in which peer support formed an important facilitator for disabled people's access to independent living at a meso (organisational) level.

## 4.2 Meso Narratives of Peer Support

Research participants explored several aspects of peer support at a meso level. Meso level governance has been described by Lowe (2004) as the organisational strata within societies. This research adopted a meso level focus and analysis as outlined in Chapter 3. The data provides an insight from what Lowe has highlighted as a unique position, whereby, for example, organisational managers are involved with both strategic planning and frontline service delivery. Peer support was outlined as a core ingredient for the development of the Independent Living Movement that resulted in collective action among disabled people to establish CILs. In Scotland and Norway some position CILs as unique user led entities that

play an important role in forging new disability related organisations that adhere to the social model of disability. They also viewed them as drivers for change within existing disability related organisations that can improve disabled people's access to independent living. Many also described that the practical implementation of empowerment relied upon peer support. This took the form of training disabled people and their families or carers around various aspects of independent living, as well as the operationalisation of full user led services through democratic organisational governance structures within GCIL and Uloba.

### 4.2.1 Peer Support and Collective Action

The organisational case study participants in Scotland and Norway outlined that the international Independent Living Movement inspired development of disabled people's movements in their countries and that these had driven the establishment of GCIL and Uloba. The principles of the Independent Living Movement took root in Berkley, California, before spreading to Europe. Peer support is considered a core element to construct and maintain formal organisational governance structures within GCIL and Uloba. As Britt (Uloba senior manager) noted, peer support acts as a linchpin for the personal development of CIL users and service delivery. Britt explained that:

> **Britt:** *"This is important because the peer counselling talking about the experience that is very, very important for disabled people to enable them to know how to be good work leaders and stuff, and for disabled people who have personal assistance themselves have experienced discrimination in society and these things are also core. These things are the grounds for doing peer support and counselling. So this is the most important thing in Uloba and that is why all of our regional leaders are peer councillors and need to have personal assistance."*

Kris (Uloba senior manager and founder) for instance, described the way that they had introduced the ethos to Norway after a trip to the United States. A Fulbright scholarship enabled this journey. It gave Kris the opportunity to soak up experiences and knowledge around access to independent living for disabled

people. A key outcome for Kris was peer networking. Adolf Ratzner, from Sweden, was instrumental in setting up some of these contacts and Kris explained that he played an important role in bringing the Independent Living Movement to Europe during the late 1970s. Shortly after the scholarship, Kris recounted another significant event that profoundly inspired him to become a founder of Uloba in 1982, "...*the mother and father of independent living, as we say, Ed Roberts and Judy Huemann came to Sweden, and I was there to meet them"*.

### 4.2.2 Peer Support and Centres for Inclusive Living

GCIL senior manager Leigh recounted the origins of GCIL. Leigh provided a first-hand account of the way that GCIL had benefited from funding that was made available in the Strathclyde region, which concurred with research by Pearson (2006). This arose from a situation whereby a local authority could only make cash payments for personal assistance services in exceptional circumstances (Witcher et al., 2000).  In 1995, GCIL was registered as a company. The key founder, Jim Woodward, drew upon previous experience of working at the Derbyshire Coalition for Inclusive Living (now Disability Derbyshire Coalition for Inclusive Living) and of setting up user led services such as the Information and Advice Line. He convinced Strathclyde Regional Council that there were unmet needs of disabled people in the West of Scotland. Fortunately, this corresponded with an unexpected funding opportunity from Strathclyde Regional Council, which established an initial six posts for the GCIL charged with administration of direct payments.

At the time of this study's fieldwork, GCIL had sixty employees. It operated out of a fully accessible headquarters based in the east of Glasgow. GCILs services have been developed across four main areas: employment, personal support, housing and training. A summary table of services and projects operating in 2012, at the time of this research, can be found in Table 4.1.

In Norway, the Independent Living Institute Sweden (2011) documented that Uloba gradually grew out of an initial user led pilot of personal assistance services involving five disabled individuals. User-controlled personal assistance did not become legal in Norway until 2000, under § 4-2 of the Social Services Act. Kirby

(Uloba founder) recounted their first-hand experience of this journey, starting with the research and organisation needed to set up the personal assistance model which guided Uloba's services prior to its official establishment in 1991.

In contrast to GCIL, Uloba concentrates solely upon the provision of personal assistance. Additionally, the organisation attracts income from the hiring out of the Uloba Freedom Express, a fully accessible coach, to external parties. Uloba also takes responsibility for running the Disability Pride parade in Oslo each year. At the outset, Kirby recalled, there was no office and Uloba used his home as their administrative base before its eventual expansion. Its initial goal was to set up four small co-operatives across Norway, covering regional areas. However, Uloba evolved to operate out of a central headquarters, located in Drammen, with a network of representatives spread over three geographical regions serving approximately 850 co-owners.

Kirby described the ways in which Uloba worked with an architect to make its headquarters fully accessible for disabled people. As an existing brick building, they had to design the internal layout. A new, bigger lift was installed that could accommodate people lying in portable beds. A bedroom on the top floor provides rest facilities for anybody during the day. For health and safety reasons, this cannot be occupied overnight. Induction loops are incorporated into each room, tactile lines provide orientation for visually impaired people throughout the building and the lift has audible announcements. Also, Kirby pointed out that wheelchair users can struggle to open doors whilst steering their chairs, and therefore electronic cards that trigger sensors to automatically open doors were installed. As well as spacious offices, the building has a dining area, conference room and a room designated for Uloba co-owners and their personal assistants, where they can, for instance, complete time sheets on the computers.

**Table 4.1 Summary of GCIL Services and Projects (Snapshot 2012)**

| Title | Description | Area | Funding | No. of Service Users |
|---|---|---|---|---|
| Open Door | An intermediate labour market project providing up to a of year paid employment for people with medium-high level of impairment. Person-centred, people on employment support allowance would expect 14 hours per week. Increasing skills/capability for full time employment. | Local | Glasgow Works and ESF | 14 |
| The Professional Careers Project | Programme for disabled graduates to help gain employment experience within Scotland's housing sector and related qualifications. | National | ESF & traineeship hosts | 17 |
| Housing Information and Advice | Assists disabled people living in, or moving to, Glasgow to explore housing options across tenures. | National | Health board, Homelessness Partnership and Big Lottery | n/a |
| Home2Fit | Online accessible housing register to assist disabled people find homes, or housing providers find potential tenants/home-owners. | National | Scottish Government | under development |

| Title | Description | Area | Funding | No. of Service Users |
|---|---|---|---|---|
| Inclusive Living Advisers | Assists disabled people with their Self-directed Support packages. | Local | Direct-payments, new individual budget or Independent Living Fund | 60 per adviser |
| East Dumbarton Independent Living Service | Assists disabled people with their Self-directed Support packages. | Local | Direct-payments, new individual budget or Independent Living Fund | n/a |
| Conference room hire | Two fully accessible rooms for external bodies to book, available within GCIL premises. | National | Service users | n/a |
| Human Resources | GCIL internal human resources, employment related advice and office affairs, such as insurance. | Local | GCIL | n/a |
| Payroll service | Provide finance advice and assistance to disabled people who employ personal assistants. | National | Service users | n/a |
| Ability Fest | Assistance with accounting for an annual event for disability related services or equipment. | Local | Ability Fest | 1000 |

| Title | Description | Area | Funding | No. of Service Users |
|---|---|---|---|---|
| Briefing Session on The Dos and Don'ts of Self-directed Support | Information and training session on producing support plans for disabled people and their families involved with Self-directed Support. | Local | GCIL | n/a |
| Briefing Session on Safe Recruitment | Information and training session on safe ways to recruit personal assistants for disabled people and their families involved with Self-directed Support. | Local | GCIL | n/a |
| Briefing Session on Being a Good Boss | Information and training session on the responsibilities of an employer for disabled people and their families involved with Self-directed Support. | Local | GCIL | n/a |
| Briefing Session on The Mysteries of Paperwork | Information and training session on the bureaucracy of Self-directed Support for disabled people and their families. | Local | GCIL | n/a |
| Rights to Reality | (In partnership with the Glasgow Disability Alliance). Information and experience of disabled people's services for young disabled people, designed to access independent living. | Local | Equalities and Human Rights Commission | n/a |

Source: Author

### 4.2.3 Peer Support and Disability Related Organisations

In accordance with Oliver's (1990) disability organisation typology,[14] as discussed in the literature review, section 2.3.2 Meso Level Governance, GCIL and Uloba differ. The data suggests that GCIL conforms to the consumerist/self-help category. This was characterised by problem solving for disabled people's issues with an apolitical stance. Contrastingly, Uloba adhered to a populist/activist typology; its goals were explicitly political in nature because it was run by disabled people for consciousness raising and collective action.

Although most case study participants in both countries talked about their working partnerships with other disability organisations, this was a stronger theme throughout the Scottish data. This may reflect Oliver and Barnes' (2012) observation that disability related organisations in the UK often compete for resources, and therefore, partnerships are an effective method for strengthening funding bids or sharing skill sets and knowledge. It should be noted that the majority of Scottish survey respondents occupied senior managerial or director level positions, whereas the majority of Norwegian survey respondents occupied managerial or junior positions within their organisations. This difference in the survey samples may have affected the extent that the Scottish participants understood the operational challenges around independent living. Whereas, there may be issues around to what extent the Norwegian participants understood the strategic challenges facing disabled people's access to independent living, and this may account for the higher rates of their 'don't know' responses across questions.

As Figure 4.1 shows, respondents to the Scottish survey highlighted that their organisations provided a range of services, such as housing advice or information. Figure 4.2 depicts the level of involvement the thirty respondents had with GCIL: twelve had a little, four a lot, three very much and six not at all. This provides potential scope for more contact, as a fifth of respondents indicated no involvement. The most beneficial outcome was partnership working (five

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[14] Partnership/patronage (organisations for disabled people, often charities working as consultants or on behalf of statutory authorities); economic/parliamentarian (organisations for disabled people, single-issue bodies lobbying for mainly economic matters or research; consumerist/self-help (organisations of disabled people, problem-solving and may not be political); and populist/activist (organisations of disabled people, political in nature and emphasise collective action/consciousness raising).

respondents).  Knowledge and policy development; benefits and user projects; and access training were each highlighted by three participants.

**Figure 4.1 Scotland: Service Types and Number of Providing Organisations**
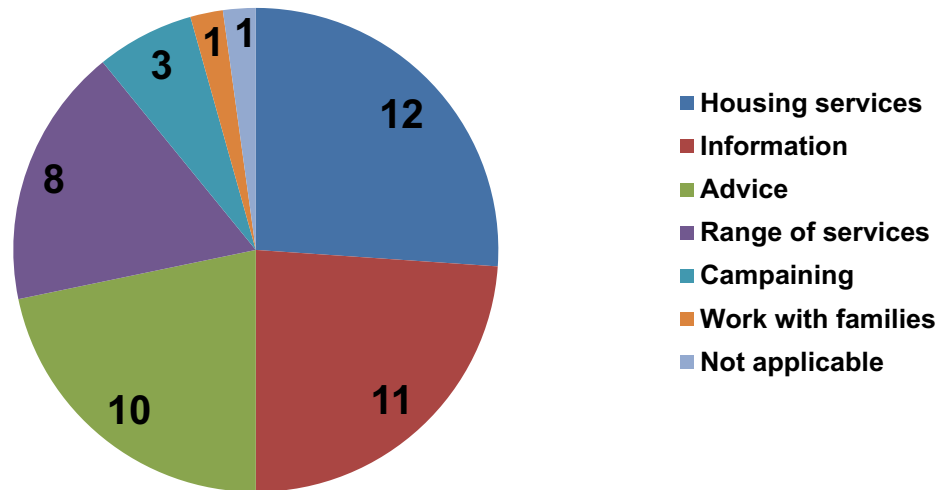


Source: Organisation survey

**Figure 4.2 Involvements with GCIL**
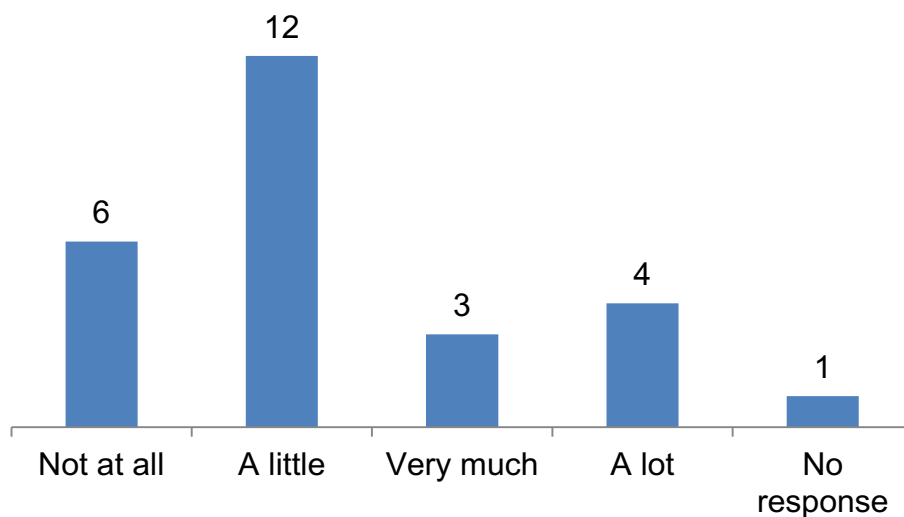


Source: Organisation survey

When asked whether there were any areas in which GCIL needed to make improvements, twenty-three of the twenty-six respondents to the Scottish survey indicated that they did not know. Two anonymous participants gave an affirmative reply. They thought GCIL needed to quicken its general response rate, especially to policy consultations, while another noted potential economic restraints that may impede efforts for the rights of disabled people and commented:

> "Their civic participation - as the major funder of GCIL is the City Council, and it is virtually providing a service on behalf of the City, it cannot be seen to be supporting anyone who challenges the City's policies or practices. It therefore fails to support disabled people's full role as equal citizens."

As Figure 4.3 shows, the most popular objectives of the Norwegian survey respondents were the promotion of independent living, closely followed by providing peer support.  Figure 4.4 depicts eleven of the twenty respondents did not know to what extent their organisations were involved with Uloba. Five indicated they were not involved at all, two said that they were a little, one said a lot and one did not answer. As outlined in Chapter 3, pseudonyms are used for the organisational case study participants to try to protect interviewees' identities within a close community. Survey responses are anonymised, unless respondents waived anonymity in order to openly support particular views or issues. The nature of involvement with Uloba varied, with Optimal Assistance highlighting networking and knowledge sharing, while the Barneombudet representative commented that:

> "We work together on Pride Parade. We are in an alliance and campaign to get rights attached to user-controlled personal alliance. We are in contact about other political issues that we share an interest in."

In the Norwegian survey, eighteen of the twenty participants indicated that they did not know if there were any areas in which Uloba needed to make improvements. According to the General Manager, User-Controlled Personal Assistance Consultant from Optimum Assistance (Norwegian Optimal Assistance - AS), Uloba needed to adopt a more joined up approach towards independent living.  At the time of the fieldwork in 2012, Uloba concentrated solely on the area of personal assistance.  The adoption of a coordinated approach towards independent living in

the future would entail expanding its service remit into other parts of disabled people's lives, such as accessible housing or equal employment opportunities. The Communications Consultant from The Children's Ombudsman (Barneombudet) suggested that Uloba needed to have greater involvement with health services across municipalities to be able to shape everyday practices within society.

**Figure 4.3 Norway: Service Types and Number of Providing Organisations**
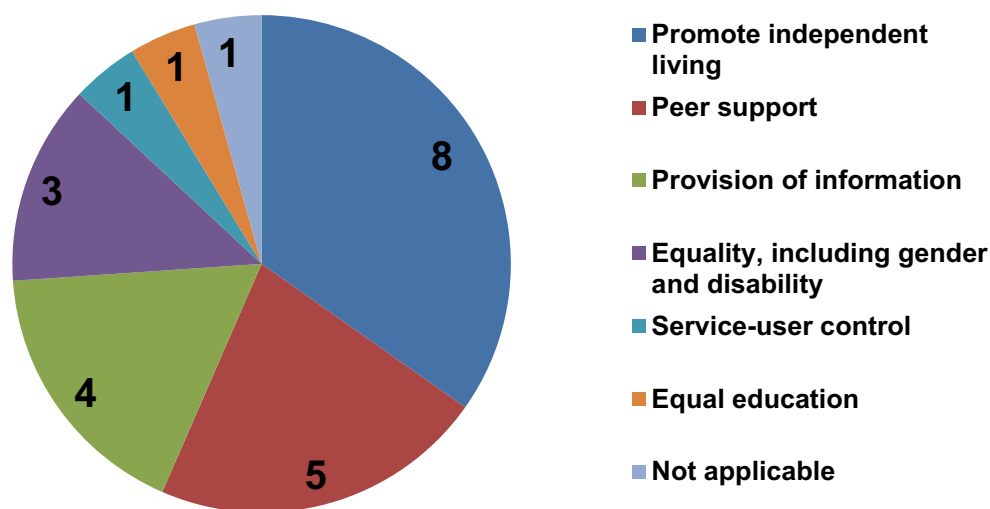


Source: Organisation survey

Participants from both case study organisations highlighted how necessary they felt it was to work with other disability organisations so that the social model of disability could be adopted. Historically, disability related organisations adhered to Oliver's (1990) category of partnership/patronage. This refers to disability related organisations or associated agencies that historically lacked user led governance and ascribed to the medical model of disability (Drake, 1999). For instance, Walmsley et al. (2000) explored two volunteer organisations in Norway that worked in the area of learning difficulties. Both fitted the profile of partnership/patronage entities and they discussed that neither had challenged the status quo nor advocated for the development of rights of people with learning difficulties. Instead, they had supported discriminatory state interventions, such as the sterilisation of disabled people.

**Figure 4.4 Involvement with Uloba**
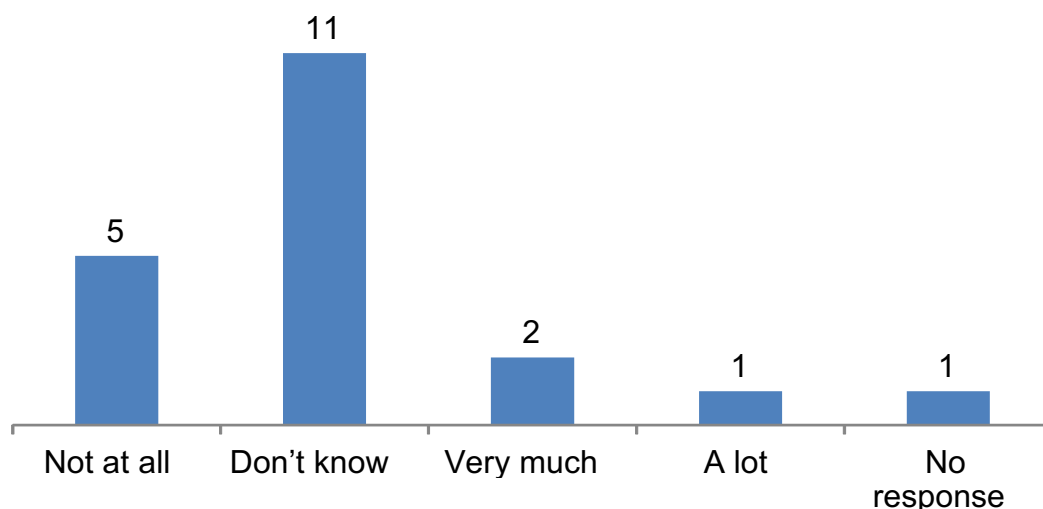


Source: Organisation survey

The Glasgow Disability Alliance, Update and Self-directed Support Scotland are examples of disability organisations that the GCIL has helped to initiate. According to senior GCIL manager Leigh, these organisations play an essential role of bridging the gap between policy and practice, actively promoting the principles of independent living in Scotland and instigating change at national and local levels. A couple of participants touched upon GCIL strengthening partnerships with established disability organisations, especially where some have begun, although slowly, to introduce disabled employees as chief executives or into senior management. As Chris (GCIL senior manager) explained, there was a lot of suspicion towards non-user led disability organisations over the past decade due to the lack of full service user involvement. Currently in Scotland, the two CILs are the only entirely service user led organisations. Much disgust was felt by disabled people at the way in which non-user led disability organisations had portrayed disabled people as objects of pity in the past to gain donations. Chris stated:

> **Chris:** *"Well the imagery was very poor and it wasn't about disabled people being seen as family members, as mothers or fathers, as employed or whatever, you know whatever positive roles that disabled people occupy now and have occupied for a long time. It was about this woman has MS.*

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*She's getting her spine ripped out. The actual adverts and posters that they used at that point ten to fifteen years ago were appalling, absolutely appalling. They portrayed us in incredibly negative ways as basically just the sum of our impairment and with nothing else positive to give or contribute, offer."*

### 4.2.4 Empowerment and Personal Assistance Bureaucracy

As outlined in Chapter 2, Shakespeare (1998) describes empowerment as the process of equipping disabled people to take control over everyday life decisions and the ways in which their choices are executed (Hillyer, 1993; Imrie, 2004). In their historical account of the development of CILs across Europe, Roulstone and Hwang (2015) have noted that empowerment involved training of new CIL members within a peer support framework; for instance, how to manage personal assistance services. The research participants were in concurrence with these research findings. They described empowerment as an on-going process and one that can involve years of training to adopt effective strategies or techniques.

Kristian (Uloba senior manager) imparted that when they had joined Uloba, it took three years before it felt as though the mechanics of independent living were understood. Personal assistance is an empowerment tool that, Kristian continued, should be controlled by the user, with autonomy over main decisions. These lessons take time to learn, especially if previous experience has been the receiving of prescribed rigid home care packages delivered by the municipality.

The process of empowerment attempts to install a sense of worth among disabled people (Kerr and Shakespeare, 2002). As many participants' narratives illuminated, at a meso level empowerment involved an examination of how resources were controlled, distributed and allocated (Gorz, 2003; Rummery, 2002). For example, both case study participants outlined the ways in which paperwork relating to personal assistance services were processed and maintained for accountability of payments. A shared theme among Scotland and Norway research participants was that often the record keeping related to personal assistance services could become excessively cumbersome and intrusive for all parties involved. However, both GCIL and Uloba provide in depth training for potential new

GCIL service users and Uloba co-owners that address management strategies required for the evidencing of personal assistance payments to service users, personal assistant agencies and individual personal assistants.

GCIL senior manager Sam explained the record keeping involved with personal assistance services for GCIL service users can span several departments. For example, Sam outlined that social work required service users to submit monitoring sheets every quarter. GCIL advisors can help to ensure that these are submitted on time and with access to copies of people's bank statements and receipts. GCIL service user Pip reflected upon some anxieties that high levels of personal assistance management can trigger for a service user, especially in relation to health and safety regulations. As Pip asserts, health and safety procedures that apply to the work place also operate in a service users' home environment where personal assistance services are being carried out:

> **Pip:** *"I'm seen as independent but you are a small employer, so all the conditions of everything that would apply in a workplace apply in your home. You've got to take all the usual precautions for health and safety as well as them physically working for you and their entitlements to things and what they can do and they can't, and the same goes for me."*

GCIL run a program of four training sessions that family can also attend. These are entitled: The Dos and Don'ts of Self-directed Support; Safe Recruitment; Being a Good Boss; and The Mysteries of Paperwork. Attracting participants, as Sam outlined, posed challenges:

> **Sam:** *"Some people were put off by the word training, simply because they'd never been in a kind of formal educational setting before; they'd maybe been in residential care or just restricted in the amount of access they had to education. ... we were calling them discussion groups and that didn't seem to work either because people thought 'oh well, we'll not really get information, we'll just be having a chat about this'. So, we're on our third title and we call them briefing sessions, where we say, 'come along to a briefing session and we give you information and then you've got the opportunity to ask questions and discuss it among yourselves".*

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Uloba regional leader, Skylar, outlined the training Uloba conduct with new co-owners related to the paperwork and record keeping encountered with the management of personal assistance services. Information is provided online, in print or in alternative formats such as Braille, along with two-day introductory courses. Then between months six and eight co-owners attend a four-day course. Skylar explained that these steps are crucial in providing the foundations for everything else. Levels of knowledge and skills are maintained through an annual regional leaders' conference, which often focuses around a specific theme.

### 4.2.5  Empowerment and User Led Governance

The empowerment of disabled people has been an objective of the governance structures of GCIL and Uloba. Both case study organisations operate a user led governance framework whereby services for disabled people are designed by and run by disabled people. According to Arnstein's ladder of participation (1969), GCIL and Uloba occupy the top rung as user led organisations. Case study research participants commented that this status is unique for an organisation in Scotland and Norway since most disability related organisations adhere to a medical model of disability that results in tokenistic user involvement (a lower rung of Arnstein's ladder of participation). Roulstone and Hwang (2015) have outlined a historical account of CILs that outline the beginnings of user led governance under the influence of the Co-operative Movement whereby the key characteristics of co-operative governance have shaped CILs across Europe, namely access to information, inclusion and participation, accountability and local organisation.

Under the Co-operatives UK's (2004, cited in Glasby and Taylor, 2006) typologies of co-operative governance, research participants described GCIL as an employee-owned cooperative. This model is whereby services are contracted from an employee-owned home support provider. Service users agree to the support provided by the co-operative and negotiate the practical arrangements themselves. The support worker and the service user are free to negotiate changes to these arrangements within the agreed framework.  In Scotland, disabled people make up 85% of the GCIL board. Only disabled people can become full members who are able to vote at Annual General Assemblies. As well as this, Chris (senior GCIL manager) explained that the organisation has sub-working groups where the

majority of members are disabled participants and GCIL regularly distribute feedback questionnaires and newsletters.

Contrastingly, research participants outlined Uloba's governance structure in line with the service user co-operative. This has been defined by Co-operatives UK (2004, cited in Glasby and Taylor, 2006) as a model whereby the co-operative may contract self-employed PAs or directly employ support staff. Service users join the co-operative as they might join a community organisation or club, and have the right to select their own support worker from those on offer from the co-operative, recruit a PA and introduce a worker of their choice to the co-operative.

Uloba founder and senior manager Tayte outlined that Uloba has 150 employees across the various administrative departments, 92% of whom are disabled individuals. At the time of this fieldwork, Uloba was undergoing a change to its decision-making structure. In January 2012, Uloba's status became a co-operative. The majority of Uloba's board are disabled individuals. Tayte explained that the main implications of co-operative status for the board were additional representatives from employees and personal assistants.

Research participants in both countries highlighted potential improvements to the case studies user led governance framework. Mainly these improvement focused upon the representativeness of different impairment groups views during the decision making process, methods of user communication and, strategies to address possible knowledge gaps between organisational staff and members. As Corker and French (1999) have noted, the Independent Living Movement had often adopted a wheelchair user-centric perspective. Case study participants remarked that GCIL and Uloba could make changes to governance structures in order to reflect the needs of sensory and cognitive impairment groups during the decision making process. Leigh, senior GCIL manager, recounted that their transition as an employee for an impairment specific organisation to GCIL, triggered at a micro level a mental adjustment towards recognition of disabled people's diverse needs. Whilst in Norway, Uloba regional leader Skylar voiced support for Uloba's progression to electronic based monitoring systems and training materials that had

increased accessibility for visually impaired users – thus helping to record the views of those with sensory impairment during the decision making process.

Research participants indicated that methods of communication could be improved to enhance the user led governance framework. Firstly, GCIL service user Pip commented that often meetings, such as stakeholder meetings, were held during the day. This made it difficult for those in work to participate in decision making. One option, Pip suggested, would be to change meeting times to evenings or weekends. In Norway, some participants would have liked Uloba to develop a rota of emergency cover for personal assistants. This rota would improve communication between co-owners and Uloba when situations arose where a stand-in personal assistant was required, as well as removing any possible stress from the co-owner to find a replacement personal assistant, often with little notice.

A shared theme across the case study participants concerned the potential knowledge gap that existed between organisational staff and members. This knowledge gap may impede organisational members to participate in the democratic decision making process because they feel less confident or informed about specific issues. Participants, such as Bronnil, outlined that Uloba employees are immersed in the organisational informal as well as formal practices; the everyday operations and underlying financial structures of the organisation. The overall concerns from research participants were summed up by Bronnil who observed that:

> **Bronnil:** *"I think Uloba in one way has a very good democratic structure, but when it comes to reality, it's not very democratic because co-owners out there in the suburbs have very little insight into what is going on in the entire organisation and that of course, makes it very hard for a co-owner to take part in the big discussions and decisions because they don't feel comfortable .... none of the co-owners have any views on the strategic questions whatsoever."*

*4.2.6 Summary*

In summary, the discussions around the role and methods of empowerment of GCIL service users and Uloba co-owners highlighted Hirst's (1994) proposition that volunteer organisations, such as Centres for Inclusive Living, are best situated at the front-line end of practice rather than the state delivering, designing and monitoring provision of services for disabled people. Narratives from Scotland and Norway demonstrated that service users and co-owners gained a sense of self-worth, as well as the knowledge and skills for self-autonomy over everyday life decisions. However, their user-involvement with the case study organisations also raised challenges around this deliberative democracy approach (Elstub, 2006).

Barnes and Mercer (2005) have raised concerns surrounding automatic user-participation that were supported by some participants. For instance, both case study organisations appeared to face the challenge of knowledge between long-term foundational leaders and users not as involved with the operational running of GCIL and Uloba. There could be an argument for both to explore different deliberation methods in order to gain the views of users with diverse needs (McLaughlin et al., 2004), since, as Barnes (2002) argued, diversity amongst stakeholders does not ensure representativeness or address potential imbalances of power relations. Further examination would need to be carried out to outline potential training or techniques to gather views that would be most effective for current GCIL service users and Uloba co-owners.

## 4.3 Macro Narratives of Peer Support

The themes surrounding peer support at a macro level discuss the extent that GCIL and Uloba influence national policy-making and the potential challenges that exist for ensuring the views of disabled people are acknowledged and included. Both organisations, as Centres for Inclusive Living, demonstrated that they act as buffers between the state and disabled individuals (Walmsley et al., 2000). However, they are user-driven and both aim to mitigate or eradicate discriminatory practices, policies and procedures within society. Participants in both countries expressed a need for their governments to recognise the needs and rights of disabled people within legislation and regulatory instruments. Therefore, an

important role for Centres for Inclusive Living was to make sure that disabled people's voices were heard during the policy-making processes and the strategic planning of service provision. A couple of Scottish participants reflected that involvement in the devolved Scottish policy-making arena was easier, compared to that of Westminster. Mostly, they felt that this was due to the country being smaller and there being fewer Members of the Scottish Parliament (MSPs) as well as it having a tighter organisational structure.

One of Uloba's former regional leaders, Aren, voiced concerns about Norway's overall policy approach. He explained that Norway used to be known as 'Sweden's little brother'. However, in more recent times, with increasing wealth, politicians were trying to show off with unnecessary extravagance. After WWII, he explained, city planning across Norway adopted a coordinated approach. He felt in Oslo, for example, contrastingly modern buildings were erected, with little recognition of their integration or impact on the surrounding area, and this was leading to a polarisation of the city: the east having less attention, being less clean and neglected, compared to the west side. Decisions tend to have commercial, short-term gains and involve complicated ownership matrixes. One of Aren's current projects is a film documentary attempting to trace the ownership of buildings located in the dock area; it aims to demonstrate the challenges of accountability and question the use of resources.

### 4.3.1 Peer Support, Policy and Engagement

During discussions with the Scottish government, the GCIL encountered partnership working with other non-user led disability organisations. Leigh remarked that conflict could arise due to differing perspectives on a particular issue. For example, People First, an organisation for people with learning difficulties, was opposed to direct payments. The People First representative felt that service users with learning difficulties lacked sufficient support, and that it was a method to push through budget cuts. After further discussion, the representative began to recognise that the budget cuts were occurring regardless of direct-payments, and that with appropriate support mechanisms in place, individuals with learning difficulties may be able to benefit after all.

The majority of case study participants from both countries described the importance of peer support to mobilise collective action. This keeps disabled people's issues visible for public awareness. A GCIL senior manager, Sam, outlined their involvement with protests, such as the "Community-charge increases putting disabled on the breadline", compared to more radical marches in the past; while Uloba senior manager, Espen, outlined his organisation of an annual Disabled People's Pride Parade in Oslo, which continues to grow.

Oliver and Barnes (2012) raised concerns about the future power of the Independent Living Movement in the UK to achieve policy change. They pointed out that regardless of strong collective peer support amongst disabled people, austerity measures tend to occur in cycles and that overall protest methods have become more subdued and controlled by corporativist bodies. Some GCIL participants concurred with those comments when they highlighted the potential challenges of keeping the Independent Living Movement in Scotland going. Many original founders are now, as they explained, advancing in years and there is a need to engage with younger disabled people to equip potential future leaders.

Post fieldwork for this study in 2012, Pearson and Trevisan's (2015) article, as discussed in Chapter 2, highlights potential new forms of protest for the Independent Living Movement, especially considering austerity measures. They outlined that the Independent Living Movement needed to evolve its campaign approach in the past: from a National Disability Income focus in the 1960s towards rights-based anti-discrimination policies in the 1990s. Pearson and Trevisan draw attention to the impact of online protests, such as those by Disabled People Against the Cuts (2016), which campaign to address welfare reforms that hinder disabled people's access to independent living, and indicate that this may become more common with the younger generation of disabled people having been brought up in an era of social media. This study was unable to explore the use of online protests by disabled people since the self-selected participants occupied older age ranges and did not touch upon this specific theme during their lived experiences of disablement.

A few GCIL case study participants touched upon the need to examine new ways of establishing initial contact with disabled people due to the closure of traditional impairment specific institutions. They noted the work currently being conducted by other disability related organisations to establish peer projects or campaign forums. For example, GCIL participant Chris noted the recent work of the Glasgow Disability Alliance, which has grown to over 300 members and holds conferences, information sessions and campaigns. However, research by Sandvin (2003) indicates that the younger generation adheres to individual life projects, with fewer collectively related to impairment type.

Similar concerns were voiced by many Uloba participants. Although Uloba exhibited more direct political action through the annual Disabled People's Pride Parade in Oslo, it encountered many challenges. Kris and Espen, for instance, remarked that access to transport and personal assistance were key obstacles for disabled people's participation from across Norway. Moreover, a few participants touched upon the effect of Norway's welfare system dampening the political fighting spirits of disabled people due to the generous disability benefits (pensions) and attitudinal barriers.

Bronnil, for example, explained that welfare ensured a good standard of living; disabled people did not starve, they had the right to a roof, entitlement to a car for assisted travel and there was a lack of societal expectations that they would attain either educational qualifications or employment prospects. They remarked that:

> **Bronnil:** *"Of course disability is linked with underprivileged position in Norway too, of course it is linked with poverty, unemployment all these bad things, but still you don't starve. You have your car, you have some kind of life so and another thing maybe it's not a very good idea to bite the hand that feeds you. After all, you're fed."*

The online survey for this study asked for participants' views on what they considered the most important role for Centres for Inclusive Living in their country. All Scottish survey respondents indicated policy development, 27% specified communication and 21% thought provision of a range of services for people with different impairments. The most popular answer amongst Norwegian survey

respondents was that they felt Uloba struggled to impact upon policy areas. The other roles Uloba performs, according to the survey respondents, included the provision of positive support, working alongside smaller organisations and the development of peer support.

In Scotland, twenty-two of the thirty respondents thought that there were policies or practices that impede disabled people's access to independent living, while this was mirrored by twelve of the twenty respondents in Norway. Table 4.2 shows that Scottish respondents identified a spread of aspects that impede disabled people's access to independent living. The most cited were devalued voluntary work, cuts to resource budgets and non-compliance with policies or GP guidance.

**Table 4.2 Impediments to Disabled People's Access to Independent Living in Scotland and Norway**

| Scotland | Number of Respondents | Norway | Number of Respondents |
|---|---|---|---|
| Devalue voluntary work | 8 | Rights to personal assistance | 5 |
| Cutting resource budgets | 7 | Autonomy | 5 |
| Non-compliance with policies or GP | 6 | Universal design in private sector | 4 |
| People's attitudes | 4 | No answer | 1 |
| Housing crisis | 4 | Access to aids | 1 |
| No impediments | 4 | Confidence building | 1 |
| General access issues | 2 | Person-centred distribution | 1 |
| Not sure/no answer | 2 | Promote equality | 1 |
| Benefit security within structure | 1 | More research and knowledge | 1 |
| Transport inaccessibility | 1 | National rights to services | 1 |
| Joined up working across sectors | 1 | Reintroduce certain aids | 1 |

Source: Survey

Table 4.2 also shows that the Norwegian respondents gave a range of views around impediments to disabled people's access to independent living. The top

answers emerged as a lack of service user involvement and the existence of exemptions in some areas, such as small businesses avoiding making accessibility measures due to expense. This echoed the challenges highlighted by case study participants. For example, the access to resources or finances was of most concern in Scotland, whereas in Norway the focus was placed upon the control and use of resources.

**Table 4.3 Scotland and Norway: Facilitators for Independent Living**

| Practices Facilitating Independent Living | Number of Respondents |
|---|---|
| Scotland | |
| Self-directed support | 9 |
| Provision adaptations | 7 |
| Provision of accessible housing | 6 |
| Partnership working with GCI | 4 |
| Affordable housing | 3 |
| Travel card | 2 |
| Access to work | 2 |
| Disabled classed homeless | 2 |
| Consultation service user groups | 1 |
| Equalities Act | 1 |
| Doubletick | 1 |
| Good practice guidelines | 1 |
| Blind people tax allowance | 1 |
| DLA | 1 |
| Database of information services | 1 |
| Handyperson services | 1 |
| Access to assistive technology | 1 |
| Access transition of disabled | 1 |
| Support current policy direction | 1 |
| No answer | 1 |
| Norway | |
| Strong legislation | 1 |
| Universal design | 8 |
| No answer | 3 |
| Control over personal assistance | 2 |
| Access to health services | 1 |
| Access to aids | 1 |
| Not sure | 1 |

Source: Survey

Conversely, twenty-nine of the thirty respondents in Scotland thought that there were policies and practices that facilitated disabled people's access to independent living; while in Norway, sixteen of the twenty respondents agreed. Table 4.3 highlights the coverage of aspects displayed by the Scottish respondents: Self-directed Support, construction of accessible housing and provision of adaptations. The table also shows that the most cited aspects by Norwegian respondents were a general strong anti-discriminatory legislation, introduction of universal design and increased control over personal assistance. These results demonstrated the need for an understanding and analysis of disability within a coordinated approach towards independent living in both countries. Such a constitutive approach, viewing an area as part of a broader picture, has been advocated by disability studies' authors Swain et al. (2004).

### 4.3.2 Summary

At a macro level, there was a consensus among research participants that in Scotland and Norway disabled people lacked the rights to access all areas of independent living. Although peer support has fostered collective action that has resulted in notable improvements for some of the 12 Pillars of Independent Living, most interviewees and survey respondents highlighted the lack of user-control over resources or finances as a key impediment for disabled people's access to independent living. This corroborates the views of Morris (2006) who noted that greater powers need to be granted to user-controlled services to address disabled people's full participation within UK society.  In addition, in an interview with Jan Andersen in 2011, he highlighted that only a quarter of municipalities offer Uloba, the sole user led CIL in Norway, to deliver personal assistance (Westberg, 2011).

Organisational case study interviewees echo the concerns raised by writers within disability studies around the impact of austerity measures on future collective action. Oliver and Barnes (2012) and Bente Skansgård (Uloba founder) (Independent Living Institute, 2011) are among those who point out that reductions to local government budgets curtails disabled people's rights to pursue social or political activities that include peer support opportunities during campaigns.

## 4.4 Significant Findings for Peer Support

Data analysis uncovered micro, meso and macro level narratives around the role and nature of peer support for disabled people. Adoption of the social relational model as the core theoretical framework (Thomas, 1999) enabled the qualitative data from interviewees and the online survey respondents to be examined for structural (macro, national) level and micro (agency) level facilitators or impediments to disabled people's access to independent living. Additionally, governance provided a useful concept throughout analysis (Lowe, 2004). For example, the organisational case studies of GCIL and Uloba produced a meso (organisational) level focus that exposed meso (user led governance policies and practice, as well as service operationalisation), at both agency (lived experience impairment effects) and macro structural (discriminatory disability barrier removal) levels of analysis towards peer support.

Research participants' views or experiences of peer support identified five key facilitators for peer support. These facilitators are depicted in Figure 4.5, the Peer Support Star, where they shaped shared identities among disabled people, the governance structures of the user led organisational case studies, the Independent Living Movement, creation of empowerment tools and disability theory. It demonstrates that in relation to the 12 Pillars of Independent Living (Spectrum, 2016) peer support acts as a linchpin for the other 11 pillars. For instance, research participants described the ways that peer support, at a micro level, instilled a shared frame of reference and that this led to collective actions with other disabled people to exert pressure for macro policy change, for instance, the Community Care (Direct Payments) Act (1996), and in Norway the legalisation of user-controlled services in 2000.

The data also showed two forms of peer support. Firstly, an informal form of peer support was evident from many case study participants and service users'/co-owners' narratives during accounts of self-identities, shared lived experiences of disablement and the ways they found out about empowerment tools such as the Centres for Inclusive Living. A characteristic was agency level explanations, with the focus upon interactions, sensations, emotions and selfhood, for instance, the

sharing of information by word of mouth at an agency level. As disabled individuals would react in different ways, peer support would be difficult to measure or quantify.

**Figure 4.5 Peer Support Star**
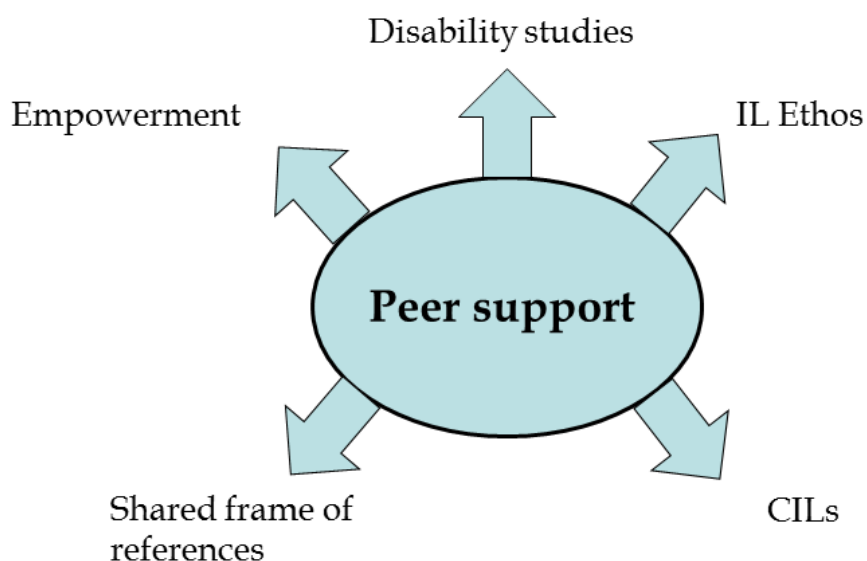


Source: Author

Secondly, formal peer support was characterised by structured peer support governance frameworks. These could be incorporated into meso or macro level policies or procedures. For example, both case study organisations are user led and all Uloba potential new co-owners undergo training with their peers before officially signing up to utilise Uloba's services.

## 4.5 Conclusion

This opening findings chapter has presented data that revealed a core theme of peer support throughout research participants' narratives. The Peer Support Star (Figure 4.5) outlines the five key ways that peer support facilitates disabled people's access to independent living. Across micro, meso and macro level expressions of peer support from research participants, peer support takes informal and formal forms: the former intangible actions such as word of mouth, and the latter tangible governance structures such as user led services.

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In addressing the overall research aims, the micro level narratives of peer support illuminated lived experiences of disablement in Scotland and Norway. Mainly, peer support developed a shared frame of reference and a sense of community with other disabled people. As reported by some research participants, the formation of an identity, especially in situations of acquired impairment, can take a long period of development. The data indicated that an affirmative identity strengthened collective bonds with other disabled people, particularly through the Independent Living Movement, and engaged them with disability theory which highlighted the ways disabled people face barriers or have rights to independent living.

There were two aspects unexplored by this doctoral research. Firstly, the online survey showed that younger disabled respondents were more likely to openly identify as disabled. This self-selecting sample cannot be generalised to the wider population nor could data gleaned from GCIL service users and Uloba co-owners be used to draw conclusions around this specific point since all were aged in their 40s or 50s. Research conducted in Norway by Sandvin (2003) suggested that, in contrast, an on-going personalisation agenda under a neo-liberal framework may be enforcing a medical model of disability, whereby the younger generation internalises blame for failing to fully participate within society.

Secondly, this research did not include the views or lived experiences of disablement from disabled people with no contact with GCIL or Uloba. A comparison between the role of peer support from their perspectives and of those in the existing data set may have revealed to what extent the disabled identity and peer support facilitate access to independent living, and even, potential alternative strategies.

The narratives of peer support at a meso level uncovered governance structures that have been adopted by GCIL and Uloba and that enhance disabled people's access to independent living. The main way that GCIL and Uloba utilise peer support is to form collective entities for expression by the Independent Living Movement to enable disabled people to take control over the delivery of services and resources (Hunt, 2001). Peer support constructs the unique user led status of

both CILs, as well as peer training on empowerment strategies for disabled people, their families and carers.

Data from the online survey showed that GCIL and Uloba have contact with other disability related organisations. Although there is scope for both to extend their influence or partnerships at a meso level, GCIL is notable in setting up disability related organisations based upon the ethos of the independent living. This means that peer support among disabled people acts as a key ingredient to displace and disrupt the dominance of disability related bodies that subscribe to the medical model of disability (Oliver, 1990).

At a macro (national, decision-making) level, research participants' narratives around peer support in Scotland and Norway demonstrate various challenges for disabled people's access to independent living. Across the 12 Pillars of Independent Living neither country exhibits disabled people's rights to all areas of life (Christensen and Pilling 2014; Independent Living Institute, 2011; Reid Howie Associates, 2007). Collective efforts and campaigns among disabled people have resulted in policy change, for instance the Direct Payments (1996) in the UK and the 2008 Norwegian Discrimination and Accessibility Act.

However, there were concerns from the majority of research participants surrounding how to attract younger generations of disabled people to keep the Independent Living Movement alive. The opportunities to foster peer support may be hindered by austerity measures in both countries. Such measures include cuts to local authority or municipality budgets, reduction in service delivery and an on-going rationalisation process of welfare distribution (Askheim, 2008; Westberg, 2011).

The following two findings chapters go on to explore accessible housing and personal assistance. These form two other pillars within the 12 Pillars of Independent Living (Spectrum, 2016). The examination will also highlight their connections with peer support and the ways that data from this research indicates that peer support acts as a lynchpin for all the remaining 11 pillars of independent living.

# Chapter 5. Accessible Housing

## 5.0 Introduction

This chapter presents the second theme of accessible housing. Accessible housing also forms one of the 12 Pillars of Independent Living (Spectrum, 2016). The term accessible housing broadly refers to properties that have been constructed to a universal design standard (Weisman, 1992), whereby full access is possible for wheelchair users. However, accessible housing remains open to interpretation and practical measures, such as the degree of accessibility, which can vary across localities (see for example Habinteg, 2016; London Borough Council, 2016).

This chapter is divided into four sections. The first section, Macro Narratives of Accessible Housing, discusses two sub-themes: disabled people's rights to accessible housing and the need for housing policy to adopt a joined-up approach towards independent living. The second section, Meso Narratives of Accessible Housing, explores to what extent GCIL and Uloba provide support to inform disabled house seekers' of financial solutions to housing. Additionally, participants discussed the resource capacity for GCIL and Uloba to deliver appropriate services and how, at a meso level, housing services can facilitate a joined-up approach towards independent living. The third section, Micro Narratives of Accessible Housing, examines to what extent disabled house seekers experience autonomy over housing decisions. The lived experiences of GCIL service users and Uloba co-owners provide an insightful account of disabled people's pathways into accessible housing. The final section, Significant Findings for Accessible Housing, reflects upon the relationship between accessible housing and the theme of peer support discussed in Chapter 4. The chapter closes with an overview of the key points raised by the macro, meso and micro level narratives around accessible housing and consolidates the ways that the evidence responds to the research questions.

## 5.1 Macro Narratives of Accessible Housing

As discussed in Chapter 2, Lowe (2004) outlined that macro level analysis involved the examination of national policies and strategic decision making processes. The participants' macro narratives of accessible housing research highlighted two sub-themes: disabled people's rights to accessible housing and the coordination of housing policy.

### 5.1.1 Disabled People's Rights to Accessible Housing

Neither Scotland nor Norway has enshrined disabled people's rights to accessible housing in national policy (Adaptations Working Group, 2012; Kangas and Palme, 2005; WHO, 2012). Research participants highlighted that a chronic lack of accessible or adapted housing stock existed in both countries, and that this would pose a challenge for aging populations. For instance, in Chapter 2, Table 2.3 (p. 30) and Table 2.4 (p. 31) demonstrated that Scotland exhibited a patchwork of legislative measures towards disabled people and accessible housing compared to Norway's sole Anti-Discrimination and Accessibility Act which came into force in 2009. Such approaches reflected Esping-Andersen's (1990) liberal and social democratic welfare typologies: under the former, Scotland emphasised self-reliance, while under the latter, Norway engaged in a collectivist sense of solidarity to proclaim housing as a social right for all (Wessel, 1998).

In Scotland, Chris' (GCIL senior manager) account demonstrated application of the social relational model (Thomas, 1999), whereby macro level Scottish housing policy changes occurred in response to agency level lived experiences of disablement. Chris outlined that in 2011 the Scottish housing strategy entitled, Homes Fit for the 21st Century, recognised some of the challenges that disabled house-seekers encountered when in search of suitable accessible properties. The housing strategy set out support to fund the development of a Scottish National Accessible Housing Register (now called Home2Fit), steered through a partnership between GCIL and Housing Options Scotland. Chris explained that the Home2Fit online register enables housing providers to short-list potential candidates for vacant accessible housing and to download potential applicant details and requirements. Chris remarked that a significant strength of Home2Fit lies in the

ability to channel resources and increase cross-boundary communication amongst local authority and health board areas:

> **Chris:** *"The social work departments don't talk to each other, they don't make referrals across political boundaries and that's why an accessible housing register Scotland-wide is so important because the resource may be in another local authority area but you may need it, you may be the person in the greatest need. And so only a Scotland-wide accessible housing register helps to ensure that those sorts of properties which have had considerable investment go to the person in the greatest need I believe."*

Home2Fit, Chris continued, was based upon GCILs existing local accessible housing register in Glasgow that had been created in response to micro level lived experiences of GCIL service users. Chris reflected that from their commencement of employment as an information officer with GCIL during the mid-1990s, many GCIL service users had come to them with problems relating to accessing their housing. For example, those with progressive health conditions highlighted difficulties with steps at entrances and a patient awaiting discharge from a spinal injuries unit was unable to return home due to living in an inaccessible flat.

The GCIL board recognised that action needed to be taken to support agency level practical and macro level policy change for disabled house seekers. At the time of field work in 2012, GCIL had two full time housing advisors and an administrator. Service users receive a full housing options appraisal, including private-rented, social-rented or home-ownership choices. As well as supporting the development of Home2Fit, Chris also welcomed the 2011 housing strategy's encouragement that 10% of new built social housing should be constructed to a barrier-free standard. Although, Chris asserted, this should be a cross-tenure requirement applied to the private rented and home-ownership sectors.

Some people, Chris acknowledged, had questioned why GCIL supported a scheme that was specialist and may perpetuate exclusion rather than improve integration of disabled people's needs into mainstream services for house seekers. This conflicted with the principles of the Independent Living Movement (Hunt,

2001) that emphasised integration and inclusion of disabled people into everyday practices (UPIAS, 1976). However, Chris asserted, the UK housing market has, to date, failed disabled people. For example, the chronic shortage of accessible housing that was particularly exacerbated in the 1980s when space standards were abolished under the Conservative government from 1987 to 1991. This led to housing developers constructing small compact properties which tended to be costly to adapt.

In Norway, under its Anti-Discrimination and Accessibility Act of 2009, key expert Audny supported the obligatory universal design standard applied to all new properties. This ensured the installation of features such as fully accessible bathrooms or an elevator for properties with three or more floors. Audny enthused that the Husbanken, responsible for funding 50% of new property construction in Norway, went a step further by providing funding for new constructions that installed an elevator if they had two floors. However, Uloba founder, Kris, discussed private builders' reluctance to comply with universal design. According to Kris, house builders' attempt to circumvent the stipulation to provide an elevator if the property has three or more floors by discounting any living space constructed below ground level.

Kris also reflected upon the recent construction of new student accommodation blocks in Oslo and highlighted that these gave an example of missed opportunities to improve accessibility. Accessibility had only been applied to ground floor areas, and this, Kris explained, had curtailed disabled students' ability to visit neighbours and socialise with whom they wished, where they wished. For instance, wheelchairs users were unable to visit their neighbours on upper floors.

Uloba senior manager, Bronnil, outlined that one of Norway's house builders, Selvaag, was campaigning against the mandatory legislation around accessible housing in Norway. According to Selvaag, universal design will be too expensive and hinder future construction. Bronnil reflected upon the connections between accessible housing, the use of resources and power relations. For instance, Bronnil pointed out that there had been a lack of protest against the additional costs incurred by updated fire safety legislation for properties. According to Bronnil, this

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was mainly due to attitudinal discrimination whereby disabled people were not regarded as autonomous beings that are able to exert decisions around where they would like to live and with whom.

### 5.1.2 The Coordination of Housing Policy

The second sub-theme within the research participants' macro narratives centred on the need for housing policy to coordinate with other policy areas related to independent living. As pointed out by French and Swain (2008), disabled people's lives comprise of an interplay between employment, housing, personal assistance, public transport, education and access to leisure activities. In order for policies to facilitate disabled people's access to independent living, they argued that a coordinated approach towards independent living was necessary to allow disabled people to simultaneously access all areas of life. Newton et al. (2006), for example, asserted that housing needs to be contextualised within a wider picture of accessibility to the external environment and individual well-being.

The narratives of interview participants and survey respondents in Scotland and Norway highlighted that policy goals can be well intentioned and ambitious but can lack sufficient implementation in practice. Participants discussed strong legislation surrounding the provision of accessible housing. Some of the examples cited in Norway included The Municipal Health and Social Care Act 2011, the Accessibility and Anti-Discrimination Act 2009 and the Planning and Building Act 2008; and in Scotland the 2011 Housing Strategy (Scottish Government, 2011) and Equality Act 2010. As the Communications Consultant from the Children's Ombudsman (Barneombudet) summed up that:

> *"We have plenty of laws, regulations and guidelines etc. which provide a good basis for promoting disability access to an independent life, but this is not reflected in reality. In other words, these rights are broken on a daily basis, legal guidelines are not followed through on and the state does not put the adequate pressure on for this to be implemented."*

A key theme that emerged concerned the lack of coordination across policy areas due to a tenure-based focus. Participants asserted that a tenure neutral approach

towards the construction of new built accessible homes and adaptation of existing stock was required to improve disabled people's access to independent living in practice. Kris, for instance, remarked that housing co-operatives may construct ten fully accessible properties within a development and fail to sell them. Then, Kris continued they conclude that there is no demand for housing by disabled people in that area. This demonstrates, Kris asserted, a failure to consider the wider accessibility issues as pointed out by Imrie (1996 and 2004), such as adequate public transport links or access to local facilities.

Kris's reflection had been discussed within the literature that draws attention to the ways in which housing shapes and gives meaning to everyday lives at a micro level (Saunders, 1989; Saunders and Williams, 1988). Saunders (1989) highlighted that while a home is meant to be a place of personal control and expression, in fact, it may impede independent living or impact negatively upon physical and psychological well-being (Haywood, 2004; Imrie, 2004). As Kris's account demonstrated, disabled people's experiences of housing are characterised by communicational, financial, attitudinal, political and environmental barriers (Hemingway, 2011; Kealand, 2010).

An anonymous Scotland survey respondent pointed out that knowledge transfer schemes could improve policy delivery within a cross-tenure approach towards the provision of accessible/adapted housing. The survey respondent explained that some social landlords have expertise in providing disabled people's access to independent living. These particular housing providers have developed strategic planning for future accessible housing, are able to enhance independent living with assistive technologies or handy-person schemes (home repairs for vulnerable groups), actively seek to maximise use of existing accessible/adapted stock through effective allocation systems (perhaps through the use of Accessible Housing Registers) and, aim to create efficient home adaptation processes. Such knowledge transfer schemes could benefit, for example, the private rental sector, architects and construction companies.

Knowledge transfer schemes across tenures could also benefit national and local strategic planning to improve the accessibility of housing, public transport links and

external environments. Uloba senior manager, Britt, highlighted that Norway's capital city, Oslo, had set out to be the most accessible area by 2010. However, those ambitions were quickly abandoned as people grew to realise the amount of work required to make it fully accessible for disabled people, and that the timescale set was unrealistic.

Additionally several other Norwegian participants echoed that the streets, public transport and public facilities lacked the inclusion of disabled people's needs and hindered access to independent living. This corroborated the findings from a study conducted by Wessel (1998) where it was noted that, due to access issues, there was an under-representation of disabled people in three main cities in Norway. However, Aren, a former Uloba regional leader, remarked that older European cities, such as Salzburg in Austria, have succeeded in implementing accessibility measures. On a visit during an Independent Living Movement Freedom Drive event, Aren enjoyed the sensation of being able to move around the whole environment, including the railway.

Scotland study participants voiced dissatisfaction concerning the lack of policy coordination towards the funding of disabled people's independent living. One anonymous survey respondent commented that:

> *"We need to get financial benefits sorted out to provide the right level of support. We need to get the balance right, where we do not only keep people alive but support them to live the lives they want."*

This anonymous respondent continued that a potential future approach could encourage the inclusion of housing budgets within Self-directed Support funding streams.

### 5.1.3 Summary

To summarise, the macro narratives of accessible housing revealed two sub-themes: disabled people's right to accessible housing and the need for housing policy to adopt a coordinated approach towards independent living. The former highlights that, to date, the consolidated Norwegian Anti-Discrimination and Accessibility Act of 2009 provided stronger legislative powers to address the

chronic lack of accessible or adapted housing in comparison to the patchwork policy approach in Scotland. However, research participants pointed out that disabled people's inclusion needed to be supported in both countries by cross-tenure policies and practices. Similarly, Scotland and Norway housing policies need to embrace, especially during the planning process, a coordinated approach of independent living. This will ensure that accessible housing is considered alongside other areas, such as accessible external environments, public transport links and accessible facilities or amenities.

## 5.2 Meso Narratives of Accessible Housing

Meso level narratives identified three sub-themes. Support to identify housing and financial solutions was discussed by many research participants involved with GCIL and Uloba. Closely linked to this theme was organisational capacity to deliver services. Participants reflected upon the extent to which GCIL and Uloba had control over appropriate levels of resources required to deliver housing or independent living related services. The coordination of housing services highlighted the interconnections between housing and other areas of independent living, such as employment and education. For instance, empowerment and inclusion involves equipping disabled people to participate in the delivery of housing services.

### 5.2.1 Support to Identify Housing and Financial Solutions

Data from the online survey showed that there were many facilitators that enhanced disabled people's access to independent living. The leading aspects for both Scotland and Norway respondents included service user control, accessibility of external environments and accessible housing across all sectors. Norwegian survey respondents also highlighted that disabled people needed autonomy in order to access independent living.

The interview data demonstrated the ways in which, at a meso level, GCIL and Uloba aimed to support the autonomy and empowerment of disabled house seekers. One key strategy that emerged was the provision of support to explore potential financial solutions and to secure appropriate accessible accommodation.

In Scotland, frontline GCIL employee Sandy described the process whereby disabled house seekers received assistance from GCIL housing advisors:

> **Sandy:** *"The individual would come in, sit with them, find out their current circumstances and obviously we've got access to a number of different housing associations here, then we just sit down and talk with them and find out how their current circumstances are, what they require and things like that, size of house, accessibility and things like that. They then take them away, they fill out the application forms for them, they hand them back to ourselves and we'll then send a covering letter."*

This was corroborated by GCIL service user Alex, who recounted the challenges they faced in finding an accessible place to live when they moved out of the family home. They first became aware of their housing options when they contacted GCIL. The housing advisors explained that individual applications needed to be completed for each housing association (there were approximately 80 in the Glasgow area) and a Community Care Assessment would put measures in place for personal assistance at home. Eventually, a housing association offered an accessible property. However, Alex described their initial hesitation to accept it because their Community Care Assessment would take up to twenty-eight days. Therefore, this indicated to Alex that there was a lack of joint working between the services:

> **Alex:** *"One of the things that was always depressing me slightly was I was thinking well, I could apply for a house, but then if I was to be offered it and accept it, there's no guarantee that I could live there, because I would need assistance to live on my own."*

Similarly, Alex spoke to the social work department and managed, after some frank discussions, to speed up the community care process. Their move into the property went ahead. However, Alex noted that they felt socially isolated, surrounded by inaccessible facilities and facing the same challenges associated with a lack of employment opportunities. Fellow GCIL service user Pip's reflections also illustrated that housing is about more than the bricks and mortar. They felt that their rights as a citizen were compromised through Scotland's approach towards

personal care centring upon basic needs, such as assistance to get out of bed, wash, get dressed, eat and drink. Life, Pip argued, was also about the quality of living independently.

At the time of participating in the study, Pip had not been affected by the cuts to local authority budgets under the austerity measures and local taxation brought in by the UK Conservative-Liberal Democrat Coalition Government in 2010. However, Pip had heard that many disabled people were effectively imprisoned without the financial support to enable a social life or participation in everyday activities, such as shopping. Pip voiced uncertainties as to whether future changes may also jeopardise their desire to live at home:

> **Pip:** *"In many ways I know I'm quite lucky with what I've got. It's basic that I manage and I get by on it. Social work have said that, if ever I was unwell for a while and needed a lot of cover or just for whatever reason things not working, and then it would become an issue. The funding wouldn't cover it."*

Pip's reflection highlighted their uncertainty about whether additional care support would be granted if their health deteriorated in the future. The potential for not enough care support at home may lead to Pip moving from their home to a care setting, such as sheltered housing or a nursing home. Contrastingly, Norwegian disabled house-seekers expressed fewer anxieties around financial support for obtaining accessible housing. Uloba founder Britt pointed out that the Husbanken played an important role for disabled house seekers. The Husbanken began in 1946 in response to the post-WWII chronic housing shortage because many properties had been damaged or destroyed. The Husbanken is an organisation that enables disadvantaged groups within society to attain home ownership. Norwegian key expert Audny explained that home-ownership was the preferred tenure in Norway in order to foster feelings of connection and belonging between people and their dwellings. Fellow key expert Jensen outlined that the Husbanken can be best described as a welfare bank responsible for supporting the construction of approximately 50% of new properties.

Jensen continued that Husbanken provided the lowest interest rates in the housing market for vulnerable groups. The not-for-profit organisation can assist with up to 100% of home-ownership finance. This is made up of various funding streams; for example, municipalities provide a housing allowance for second-hand properties, start-up loans and grants. However, more recently home-owners had encountered rising house prices and tended to find more affordable housing located outside of the main cities. In addition, many Norwegian homeowners based their acquisition costs on renting out half their property, which they are able to do tax free. For example, a common strategy for homeowners was to create and rent out a basement flat.

Research participant Asle shared their experience of acquiring suitable accommodation for their daughter who has a cognitive impairment. Asle had become aware of a flat for sale in their block and investigated what purchase options were available. The Husbanken agreed to provide a loan, and this, along with money from their municipality, meant that mortgage payments would finish after ten years. Asle stated that the process had been very simple and had only taken five days. The flat was bought for 1.8 million kroner (KR) (£152 000); 1.3million KR (£109 600) from the Husbanken and 500 000 KR (£42 000) from a housing cooperative. A start-up loan, operated by the state, was administered via their municipality for 300 000 KR £25 000) and the only adaptation required within the flat was the installation of a corner bath. Asle declared that:

> **Asle:** *"I was surprised myself at how easy the whole process was. I don't understand why all these parents don't go to the bank for loans to give their child independent living; it's so easy to buy it. Then you get, you don't get poor because you've got your own flat and they can't come and say you need to go to an institution you have your own space."*

According to Asle, although the Norwegian local municipality staff involved with the home-ownership grants were supportive, they were surprised at the ambition of Asle's daughter to live independently in her own flat. This may reflect the dominance of the medical model of disability (Drake, 1999), whereby professionals may perpetuate attitudinal assumptions that disabled people should stay in

institutional accommodation and be cared for instead of exerting autonomy over their everyday life choices (Oliver, 1990). Asle's disabled daughter's experiences demonstrate the interconnections between accessible housing and access to information, which also forms one of the 12 Pillars of Independent Living (Spectrum, 2016). This study supports the findings of previous research, such as MacLean and Guy's (2015) examination of disabled people's pathways into housing in Scotland and Ytrehus's (2011) study on housing for the elderly in Norway that highlighted issues at a meso (organisational) level around the dissemination of relevant information to disabled people and their families at a micro (agency) level.

Asle's daughter helped cover mortgage payments by renting out the garage and working at Uloba. In addition, she reduced her living costs by, for example, limiting the use of her phone, collecting fire wood from her father's farm and not eating too much. Asle also recalled an experience of looking for a family home when her daughters were younger. They encountered challenges to finding a wheelchair accessible property:

> **Asle:** *"Me and my husband had been looking to buy a house without stairs; it's like one in one-hundred that has no stairs, it's so difficult. I met another couple at the bank who were after the same house so we had to go up in price. I support a group of children who have impairments and one of the mothers was asking where do you live? And I told her and she said that's the house that we tried to buy. Of course, because they had a child in a wheelchair too. (...) you need to invite everybody to your house all the time because it's impossible to go anywhere else."*

### 5.2.2 Organisational Capacity to Deliver Services

Research participants highlighted that GCIL and Uloba's organisational capacity to deliver services impacted upon disabled people's opportunities to acquire accessible housing. In Scotland, GCIL case study participants noted the ways that the organisation tried to develop and maintain a housing information service. However, several participants pointed out that the housing information service has been affected by the general scarcity of funding for the voluntary sector. This has

a profound effect on service delivery since, as Kasey (a senior manager) highlighted, GCIL tended not to make much of a surplus. Kasey also explained that any surplus was usually consumed by a deficit the following year. Therefore, GCIL has restructured service priorities in order to meet the criteria of various funders. Senior manager Chris explained that, for a third-sector organisation, funding could be difficult to procure. A housing information service failed to register with any potential funders' priorities, and thus, Chris outlined GCIL's strategy to attract financial support:

> **Chris:** *"Instead of housing and employment being two separate services, we've now amalgamated them. And we now have an employment and housing service in one big department. Now what that's enabled us to do is politically set key priority groups to get people off benefits and into work. That is a major political driver. That then feeds down into charities and funders like the big lottery so that's now one of their key priority groups. Employability: so we've reconfigured our service to say that all of our advisors will provide employability and housing advice. So in the funding bids you say that the focus is on employability. We will help disabled people with employability and you de-emphasise the fact that you might do 15 housing applications. You might have to work hard to get the electric wheelchair etc. etc., you de-emphasise all that because they're not willing to fund it. You focus on employability stuff which they are willing to fund and that's the huge change that's taken place because they just won't fund £150 000 worth of housing and employment advice."*

Conversely, many Norway participants touched upon greater opportunities for support packages to assist disabled people to finance accessible housing solutions. They pointed out their country's wealth was due to the oil industry and a generous welfare system because of higher taxation rates. Uloba, for instance, receives financial resources from one main avenue. Funding comes indirectly from the Norwegian state through the personal assistance model that underpins the organisation's operation. It relies upon local municipalities to provide finance for service user packages. The employer is the service user and Uloba takes the role of administrator, advice giver and supplier of training and legal support. However,

obtaining contracts could be a challenge. The choice of whether service provision will be facilitated by Uloba or by another organisation is firmly in the hands of municipalities and not service users (Westberg, 2011).

Britt, senior manager and founder, outlined that Uloba was a rich organisation. Britt outlined that some non-disabled people track Uloba's progress in order that they might find an opportunity to undermine the ability of disabled people to operate such a large and financially successful organisation. The stability of Uloba's finances meant that occasionally Uloba explored innovative activities that hold potential financial risks where nondisabled antagonists may be able to question the cost effectiveness of some actions undertaken by Uloba.

Bronnil (senior manager) described a particular activity that created tensions within the organisation concerning cost effectiveness. 1.5 million KR (£126 000) was spent on taking the Uloba Freedom Express to visit 20 Norwegian towns under-represented in Uloba. Uloba representatives spoke with the disabled citizens and the town mayors about the independent living ethos and Uloba services. Six months later, Uloba reviewed the outcomes of the activity. Unfortunately no new co-owners joined Uloba from these specific 20 Norwegian towns that are under-represented within the organisation. However, Bronnil remarked that some Uloba staff and co-owners argued that the effects from the activity were immeasurable, for instance it increased people's general awareness of the personal assistance service and the rights of disabled people to live independently.

### 5.2.3 The Coordination of Housing Services

Survey respondents in both countries touched upon the need for a coordinated approach of independent living. For instance, a student from Sør-Trøndelang Regional Municipality (Sør-Trøndelag Fylkeskommune) acknowledged the need, at a meso level, for disabled people's empowerment of service delivery to be supported by equal employment opportunities. They wrote in the Norwegian survey that they wanted:

*"for private companies and the state to implement universal accessibility design as much as possible to help those who aren't employed but who can work. The Støttekontaktsystemet (support network system) is brilliant, build upon this."*

GCIL and Uloba maximised employment opportunities for disabled people to nurture a sense of worth, build upon their self-esteem and demonstrate their abilities to contribute towards society. For example, there were various employment schemes amongst the range of services delivered by GCIL and one of these related directly to housing. Senior manager Chris outlined that the Professional Career Initiative, a positive action path model, sought to address the under-representation of disabled people employed at a professional level within Scotland's housing sector. The project placed trainees with a host organisation for two and a half years.

GCIL service user Alex was a professional career trainee. They described having heard of the programme via a disability advisor at the local job centre. Alex had left education without attaining many qualifications and had been unemployed for around ten years. Any interviews, Alex recounted, tended not to go well due to their lack of confidence and lack of awareness of assistance through, for example, the Access to Work scheme. Instead, Alex focused upon voluntary work to build up experience; for example, designing a website for the Disabled Person's Housing Service in East Renfrewshire. The Professional Career Initiative involved Alex spending three years with a housing association in Glasgow before moving to their position, at the time of the study, at a tenant related organisation. Alex described their duties:

> **Alex:** *"I mean, at the [housing association in Glasgow] I was just kind of doing reception duties and inputting data for housing allocations and things like that, whereas every day's slightly different in [the tenant related organisation]. As I said, my main role is producing information material for tenants, but it can be ... I do a range of things and I'm always included in team meetings; they ask my advice and they ask what I've been doing and what kind of reading notes I think we should be doing. So I'm treated more*

*... I don't know if you can say, more of an equal than I was within [housing association in Glasgow]."*

In parallel, Alex undertook a master's degree in housing studies. Alex recounted important changes that helped to balance their studies and work. During service user feedback, many participants highlighted that they came onto the scheme without a housing background. Alex explained that it was important for people to receive enough study time in order to grasp new concepts while gaining an overview of Scotland's housing system. Alex outlined that their dissertation had examined why people joined groups and the ways in which some groups were more influential than others, especially within the housing sector. However, Alex expressed concerns about whether an employment opportunity would come along in the future. They remarked that:

**Alex:** *"Well, I'm eternally grateful to GCIL for giving me the opportunities. My saying in life, I'm not ancient but I'm 57 in two weeks and I'm still making £6.05 an hour which kind of really annoys me. Basically if I get this qualification, for example, I'll be the most qualified person in my family and the least paid. Now a job isn't all about the money but it's a reflection of your worth."*

GCIL service user narratives indicated that financial risk featured heavily in housing decisions and these were entwined with other life choice decisions. For instance, Jessie was worried that if they started working under the new welfare changes they may need to move to a new house and, at present, they were satisfied with the status quo. Jessie participated in various types of voluntary work, particularly around improving disabled people's access to services, and noted that:

**Jessie:** *"The employment's a tricky one because the way it works for me with the level of support I've got, and the way that it's made up, that if I was to work you would lose the support, you know, so there's no point taking the work context on board, but I do a lot of voluntary work."*

Jessie's account highlights the complexities exhibited by the UK welfare system. For instance, entering employment can result in the loss of some benefits but can

act as a gateway to eligibility for claiming other benefits (Anderson, 2011). Although Uloba service delivery lacked direct connections with employment schemes, many participants' narratives highlighted the interplay between their housing situation, choice of where to live and other areas of life, such as employment. Uloba senior manager and founder, Kirby, explained that the organisation tried to engage as many disabled employees as possible. However, this had proven to be challenging since, as Kirby continued, disabled people often lacked the necessary educational background. Echoing these observations, Bronnil, another senior Uloba manager, remarked that the Norwegian welfare state failed to encourage positive disabled role models for disabled children. Bronnil asserted that:

> **Bronnil:** *"It also has to do with our welfare system if you're a disabled child I think, hopefully this is getting better, of course when nobody says to you when you're 8 years old what will become of you when you are older? If nobody expects anything from you then of course you will not expect anything from yourself. You will not picture yourself as a disabled person who has work, you won't picture yourself with responsibilities, you would only picture yourself as a user, and you would only picture yourself as a consumer of the welfare system. And I'm not saying that that's the entire explanation, but I think that's something."*

This was reflected in the lived experience of disablement highlighted by former Uloba regional leader Aren, who outlined their journey of setting up a business and residence in Oslo. This was met with surprise by many non-disabled individuals. Aren left working with Uloba to set up a cafe in Oslo with a small shop at the back. This involved making adaptations to the premises to make it fully accessible. Aren reported that because the municipality found the situation unusual they monitored how much profit the business made and deducted this from Aren's disability pension (benefit). Therefore, their disability pension was continually adjusted in order to maintain a balanced amount. Aren's narrative of entering paid employment lacked reservation or apprehension at putting their benefit income at risk. Furthermore, the Norwegian disability pension enables recipients to automatically resume their previous entitlement if they stop claiming for a period of time. Thus, people do not have to re-apply or be re-assessed.

Norwegian survey respondents also highlighted that society needed to provide appropriate levels of personal assistance to support disabled people in employment. Participation within work formed a prominent theme among interviewees. For example, one anonymous participant commented that: *"I believe that having a job is important in order to live an independent life."* Another called for further measures to provide a financially stable and supportive environment for disabled people to enter and maintain employment. This, they continued, would increase their participation within society and reduce inequalities of life choices, such as the ability to afford a mortgage.

### *5.2.4 Summary*

To summarise, the meso (organisational) level narratives examined three sub-themes. Research participants outlined the ways in which GCIL and Uloba enabled direct or indirect assistance to identify potential financial solutions to obtain or maintain accessible housing. GCIL provided this support through a housing information service, while Uloba tended to sign-post disabled house seekers to the Norwegian State Housing Bank (Husbanken) to receive person-centred financial packages.

However, GCIL's wider scope of services resulted in continual efforts to secure competitive funding opportunities, compared with Uloba's concentration on a personal assistance model and secure financial funding stream from the Norwegian state. Additionally, both organisations exhibited differing degrees to which housing services were coordinated with other areas of independent living. GCIL, on the one hand, provided employment opportunities for disabled people, not only within the organisation but through positive action schemes (some of which were based in the housing sector), while on the other hand, Uloba provided internal opportunities for disabled employees and focused on promoting change to the Norwegian educational attainment standards for disabled learners.

## 5.3 Micro Narratives of Accessible Housing

The micro level narratives highlighted three sub-themes. Firstly, GCIL service users and Uloba co-owners explored housing and autonomy, where attitudinal

assumptions from housing providers or family, created challenges to access suitable housing. Secondly, the theme disabled people and housing options revealed divergent lived experiences of disabled house seekers in Scotland and Norway. Finally, accessible housing experiences and independent living exposed the impediments, as experienced first-hand by research participants, to disabled people's access to independent living without housing being situated within a coordinated approach towards independent living.

### 5.3.1 Housing and Autonomy

The personal accounts from research participants illustrated the ways that peer support from GCIL and Uloba helped strengthen autonomy over housing situations. One of the most common challenges cited involved disabled people aiming to stay at home with support, instead of moving into residential care. Often, disabled people struggled to be in control of their resources and everyday life decisions. For instance, Alex, a GCIL service user, felt empowered by the GCIL ethos because disabled people were recognised as contributors towards society, as opposed to passive recipients of services (Spandler, 2004). As pointed out by Duffy et al. (2010), disabled people need a person-centred approach towards empowerment whereby they can determine what level of support and what model of care suits their circumstances. This prevents a blanket strategy for every disabled person and recognises that other significant individual identifiers, such as gender, age or ethnicity, play a role in the overall picture of empowerment needs (Corker, 1999). In other words, Alex's viewpoint echoed the objectives of the Independent Living Movement whereby disabled people campaigned for the right to influence policy and practice developments (Hunt, 2001). For example, pressure from disabled activists during the 1990s resulted in the implementation of the Community Care (Direct Payments) Act (1996).

Alex's viewpoint was mirrored by former Uloba regional leader, Aren, who noted that Norwegian municipalities frequently believed that:

> **Aren:** *"… it's the cheapest thing to put us away. They don't see us as a resource. Instead that we can provide money, they want to put us away, so yes, it's a little bit better now because of Uloba."*

In this quote Aren touches upon the notion of not being perceived as a resource by society. By this Aren meant that society ignores disabled individuals' capacity to contribute to communities in terms of knowledge, life experience, paid employment or voluntary work. Instead, Aren suggests that attitudinal prejudices, based upon the medical model of disability (Drake, 1999), still perpetuate a societal approach and disabled people are regarded as 'damaged' or incapable of decision making.

All participants expressed, in different ways, the need to move out of the family home, but to maintain a sufficient level of contact. This demonstrated that space acted as an important tangible boundary between participants and others, so that participants could exert control over their personal care needs. For example, GCIL service user Pip outlined their relationship with their family. Of particular importance was what Pip referred to as normal family activities, which they would embark upon, such as holidays or going on regular shopping trips. Eventually, after observing disabled friends apply for support to live independently, Pip moved to live around the corner from their parents. This enabled personal space but also the security of the knowledge that a family member would be nearby if an emergency arose.

The Norway co-owners' narratives echoed the experiences mentioned above. Uloba senior manager Britt imparted their experience of moving away from the family home and feeling determined to demonstrate, not only to friends and family, but to the municipality, that disabled people can live independently. Britt explained:

> **Britt:** *"Actually it was the municipality who had a place I could rent for a while. Not for free, rent, and I applied for that because I thought it was important for me to come out of my parents' house, not because I didn't get along with them, got along very well, but you know to try to be independent and also show, be visible for the municipality to say that I need independence what kind of assistance or system around me I would need to be able to do that. If they see a lot of families do a lot of things, well they're not so eager to get you anything else, any other help so you become very*

*dependent upon your family and friends. And they get much attached; they lose their freedom as well."*

### *5.3.2 Disabled People and Housing Options*

The lived experiences of GCIL service users and Uloba co-owners revealed divergent pathways into accessible housing. The Scottish service users shared their journeys of obtaining social-rented housing. GCIL service user Jessie spoke about their search for a house that involved completing many housing application forms to various housing associations across Glasgow. At first nothing materialised until Jessie contacted the local Member of Parliament to gain support. Then the local authority offered a house. Jessie recounted that an occupational therapist had the job of viewing the property and assessing its suitability for Jessie's needs.

> **Jessie:** *"You'll fill in the application form stating what you would require, then following on to that you don't actually see any house as such to view the same as anybody else would do it, until an OT has seen the house first. Going by the application form, she then would then say it was alright, so therefore I would then view it the way you would normally view it, as someone that wasn't disabled."*

Jessie's account of finding suitable accessible housing raised issues around disabled people's access to information and control over decision-making processes. Disabled people's rights to access information forms one of the 12 Pillars of Independent Living (Spectrum, 2016). However, Jessie pointed out that implicit practices can exclude them from the initial assessment process with regards to a property's level of accessibility. In practical terms, this raises a challenge with a co-production approach (Scottish Co-Production Network, 2016) whereby disabled people lead or work in partnership with others during decision making.

Jessie recounted that the original kitchen was modernised but had an inaccessible design. For example, the sink did not have space underneath to accommodate a wheelchair. Apart from the kitchen, Jessie reported feeling satisfied with the overall layout of the house and concluded that:

> **Jessie:** *"Well it's a three apartment and it's got the ramp and it's got door automatic, you know, door entry so that I can just press a key and the door opens and closes, which is a big thing because it'd take you all day to shut the door when you're coming in a narrow hallway, you know, your back's to the door then you've got to try and go up to the top, turn it and then shut the door; and the process of that you don't know who's maybe coming at your back – not that I stay in a rough area but you can't take any chances."*

Contrastingly, research participants in Norway described different routes into home ownership. Uloba founder Tayte shared an experience of buying a plot of land near family and designing and drawing the plans for the house. As well as their wage from Uloba, they had funds from an insurance claim. Tayte knew how much space they needed to move around and for equipment. However, Tayte noted that affordability was a potential barrier for disabled people wanting to construct their own fully accessible dwelling:

> **Tayte:** *"Yes it's expensive because it depends on where you want to live. In a main city like Oslo for example, it's not easy to buy land. You can buy a house or an apartment or something. When you come out of the larger capital, there is land. But to date, well at that time I bought the land for half a million, 500 000 KR (£42 000), and at the time that was quite a lot and now it's even more, one million KR (£84 000), and then you start building and that costs, maybe three or four million KR (£253 000 or £337 000), it depends on what type of house you build. And I could do that because of the insurance money. Otherwise I don't know how especially the young people today can afford to do that today. You need to be, you need to be dependent on two incomes at least and take out a big loan with the bank and they have much more, and people get into trouble where they have a high standard and it's expensive."*

Norwegian key expert, Audny, imparted their personal experiences that involved a struggle to support their brother to stay in his current accommodation. Audny explained that their brother had a cognitive impairment and lived in a Rudolph Steiner type settlement with a group of people with similar needs. Audny spoke

about the challenge they and other families had mounted towards the proposed closure of the site under the de-institutionalisation agenda. Residents shared a dining area and kitchen and had twenty-four hour staff presence and access to a private bedroom.

Audny felt that their brother benefited from continual companionship. Moving to live alone in another community would, Audny continued, be potentially very unsettling and disrupt his familiar routine. Every day he was used to having breakfast with others, singing and looking forward to participating in various activities such as cooking or making candles. Although Audny recognised the necessity to ensure independent living for disabled people, and that de-institutionalisation forms part of this movement (Kielland, 2010; Means et al., 2003; Tøssebro et al., 1996), they strongly believed that the shared development provided the best access to independent living for their brother. At the time of writing, their concerns have been listened to and the development remains intact.

This personal account captured the historical approach towards the housing of disabled people. Both Scotland and Norway adopted an institutionalisation agenda, particularly during the 19th and 20th centuries, which segregated disabled people from the able-bodied work force (Kielland, 2010; Means et al., 2003; Tøssebro et al., 1996; Walmsley, 2000). Such an approach failed to recognise that the boundary between impaired and non-impaired was often arbitrary, open to interpretation and subject to fluctuation (Shakespeare, 1998). Consequently, segregation of disabled people into 'special needs' housing or specific geographical communities failed to implement inclusionary practices and safeguard disabled people's rights to access all areas of independent living.

Although the Independent Living Movement from the 1970s had propelled collective efforts of empowerment across Europe (Shakespeare, 1996), a wheelchair user-centric perspective became dominant (Hillier, 1993) and marginalised the experiences or views of individuals with cognitive impairments. As research conducted by Davidson et al. (1999) showed, some people with cognitive impairments appreciate the institutional design where peer support provides security and promotes emotional well-being. The important aspect that

must be incorporated is empowerment (Shakespeare, 1998), regardless of the physical environmental construction whereby people with cognitive impairments have control over everyday life choices.

### 5.3.3 Accessible Housing Experiences and Independent Living

Chapter 2, the literature review, pointed out that since industrialisation across Europe, accessible design has tended to be overlooked or marginalised (MacFarlane and Laurie, 1996; Nielsen and Ambrose, 1998; Sapey, 1995; Sapey et al., 1999). This had resulted in many public environments creating physical barriers to disabled people's participation within society (Bull, 1998) and affecting decisions around where disabled people could live (Hemingway, 2011). These tensions were apparent throughout the lived experiences of GCIL service users and Uloba co-owners, especially during discussions of whether an accessible house is located in an accessible environment with accessible transport links.

GCIL service user Pip commented that excursions often required planning. Spontaneity was not an option due to the inaccessibility of many public places or modes of transport in Scotland. GCIL service user Jessie reflected that in the past disabled people were unable to access public transport at all. For instance, Jessie explained, train travel involved a trip in the guard's van at the back or being lifted onto a seat. Then assistants would often forget to unload Jessie's wheelchair at the destination. Contemporary train stations now have turnstile design barriers and these can be difficult to navigate in a wheelchair or often they are unmanned, which prevents access. Jessie denounced the stipulation to book for disabled person assistance and asserted that:

> **Jessie:** *"...I'm not a believer of having to book in advance, to me you should be able to turn up and go on same as anybody else, but this idea of booking in advance and having to plan things. Nobody else normally has got to plan things to such an extent, and they're not always there to assist you anyway. I've had many a horror story going by train."*

Former Uloba regional leader Aren had been prevented access onto a train when the ramp could not be found in time, and during another journey the ramp had been

too unsteady for the wheelchair to mount. Similarly, Uloba founder Kris expressed strong disapproval of the modern trains in operation in Norway at the time of this field work. The design excluded disabled people from integration and could even exacerbate health conditions. As Kris explained:

> **Kris:** *"The new trains, those great Italian trains you have to go beside the baby trolleys at the back, so I'm in a parking lot and people are in their seats. Very unsocial business and the parking bay is at the door, the automatic doors, and people walk in, babies are there or kids and their playroom is at the other end and I think twice I have caught pneumonia because no matter how many clothes you put on it's the draughts. Terrible draughts!"*

Bus travel in Scotland and Norway also posed a challenge for participants due to the lack of coordination of accessibility construction by private builders or local planning departments. Reese (Scotland key expert) commented that a positive had been the introduction of accessible buses. Reese never believed that such a change would happen in their lifetime, with the government enforcing companies to financially ensure accessibility. However, the majority of disabled participants reported negative issues. GCIL service user Ali disliked the uncertainty about whether an accessible bus would arrive. Ali remarked that sometimes it took a while to wait for an accessible bus that lacked the stairs at the entrance and that parents with young children often refused to fold their prams down to allow Ali to manoeuvre their wheelchair into the designated wheelchair space. This account demonstrated that at a macro (national policy) level, accessible design and inclusion remained an issue that needed to be practically addressed throughout meso (organisational) level planning processes and construction of housing developments.

Norwegian participants echoed these experiences. One Uloba service user expressed frustration at the uncertainty surrounding whether an accessible bus or tram would be operating; while Uloba founder Kris reported that unhelpful bus drivers often meant that disabled people headed for the bus station to ensure they could gain entry to the vehicle. Uloba senior manager Britt explained that although Norway had introduced an Anti-Discrimination and Accessibility Act in 2009, it

would take a long time before the current stock of inaccessible buses and trams were ready for renewal. Until then, Britt commented, many disabled people preferred to apply for funding from the state to receive a car. Consequently, many forgot about or felt disconnected from remonstrating that Norwegian public transport should be fully accessible.

### 5.3.4 Summary

To summarise, micro narratives of accessible housing illuminated three sub-themes. Research participants highlighted the importance of autonomy over housing decisions. For some, this involved challenging attitudinal assumptions held by family or housing providers. Divergent pathways into accessible housing were apparent in Scotland and Norway. Scottish participants described journeys of applying for and maintaining social housing tenancies, while in Norway interviewees outlined their experiences of entering home ownership. The lived experiences shared by interviewees and survey respondents also illustrated the need for an integrated approach to coordination of accessible housing design with the surrounding environment. For example, an accessible property needs to be located within an accessible external environment with accessible public transport links in order for a disabled person to fully access independent living.

## 5.4 Significant Findings for Accessible Housing

Data analysis of macro (national policy), meso (organisational) and micro (agency or individual action) level narratives revealed key findings in the study of disabled people's access to accessible housing and, more widely, disabled people's access to independent living in Scotland and Norway. Firstly, research participants lived experiences provided a snapshot of the barriers and facilitators that existed for disabled people to acquire appropriate accessible housing.

Secondly, this illuminated areas of corroboration with the literature review presented in Chapter 2, as well as potential avenues for further enquiry. Thirdly, the evidence suggests that peer support acted as a fundamental ingredient to enable effective individual action to resolve housing situations and influence change to policy or practice in line with the independent living ethos.

As outlined in the methodology (see Chapter 3), the aim of the field work was to gain a snapshot of the barriers to and facilitators of disabled people's access to independent living. Research participants provided insights through their accounts of the lived experiences of obtaining accessible housing in Scotland and Norway. Since the GCIL service users and Uloba co-owners comprised a self-selected sample, the perspectives of individuals with locomotion impairments dominated the findings. Further research would benefit from exploring the barriers and facilitators in relation to people with cognitive and sensory impairments in order to gain a deeper understanding of issues that affect broader groupings within the disabled people's community.

The field work for this research was carried out in 2012, and indicated that there had been a lack of significant change, in practical terms, to improve the lived experiences of disablement in Scotland and Norway. For example, Reid Howie Associates (2007) and Westberg (2011) uncovered attitudinal, communicational, financial, political and environmental impediments that many research participants outlined still exist during their reflective accounts.

In addition, authors including Hemingway (2011) and Imrie (1999, 2004 and 2006) had published accounts of the barriers facing disabled house seekers in the UK. This study's research participants echoed the challenges highlighted by these previous research studies, for example, attitudinal, financial, communicational, environmental and political impediments still exist to securing suitable accessible properties. For instance, at macro (national policy) and micro (agency) levels interviewees and online survey respondents emphasised the need for accessible housing to be included within a coordinated approach towards independent living (French and Swain, 2008). Without this, GCIL service users and Uloba co-owners living in accessible housing reported impediments to the access of independent living due to, for example, inaccessible external environments or inaccessible public transport links.

It is important to acknowledge that since the time of field work in 2012 additional research literature has been published. MacLean and Guy (2015) corroborated the personal accounts uncovered by this study and pointed out that key barriers still

existed around property finance, property supply and household composition. MacLean and Guy provided a deeper insight into the governance analysis of the facilitators for disabled people's access to accessible housing. Although Roulstone and Hwang (2015) outlined the development and role of user led Centres for Inclusive Living, particularly within the area of strengthening disabled people's rights to personal assistance, the evidence presented here expanded the focus into other areas of independent living such as accessible housing.

The application of the social relational model of disability (Thomas, 1999) supported by cross-strata governance analysis (Lowe, 2004) deepened the insight into the role of user led organisations, such as GCIL and Uloba, in the process of disabled people accessing appropriately designed housing. In this way, research participants' macro (national policy), meso (organisational) and micro (agency) narratives around accessible housing interconnected with the role of peer support. As outlined in Chapter 4, peer support was one of the 12 Pillars of Independent Living (Spectrum, 2016). The evidence from this study suggests that peer support was highly significant as a foundation for the other eleven pillars of independent living, including accessible housing.

The solutions or strategies deployed by research participants to obtain or maintain access to suitable accommodation required meso level peer support to facilitate effective individual action. At an agency level, participants such as Uloba co-owner Britt drew upon role models from Uloba to move out of the family home and challenge attitudinal assumptions that living within the community would be too much of a challenge. At a meso (organisational) level, research participants utilised the support that GCIL and Uloba provided in relation to identifying potential financial avenues to help obtain or maintain accessible housing. In Scotland, this was directly through GCIL's housing information service, while in Norway, Uloba directed disabled house seekers and their families to the Husbanken. At a macro level, collective pressure through peer support among disabled people still strived, in both countries, to make accessible housing a right for all disabled people and ensure that housing policy is coordinated with other areas of independent living, such as accessible public transport. Collective campaigning by GCIL and Uloba has resulted in policy change. The 2011 Housing Strategy provided Scottish

government funding to develop a national Accessible Housing Register (Home2Fit), whilst the Anti-Discrimination and Accessibility Act of 2009 had introduced universal design to all new built social housing in Norway.

## 5.5 Conclusion

This chapter presented the second findings, accessible housing, identified by research participants' narratives. Accessible housing also formed one of the 12 Pillars of Independent Living (Spectrum, 2016). A social relational analytical framework (Thomas, 1999) was adopted to explore the theme of accessible housing and revealed structural factors as well as lived experiences. As outlined in Chapter 4, peer support provided a foundation to facilitate disabled people's access to accessible housing and more broadly, access to independent living. Across macro (national policy), meso (organisational) and micro (agency) level accounts of accessible housing, research participants demonstrated application of 'pliable' and 'rigid' forms of peer support. 'Pliable' peer support denoted informal, intangible actions, such as word of mouth that provided, for example, a role model to support some disabled participants to secure housing within the community. 'Rigid' peer support denoted formal, tangible governance structures, such as user led housing option services.

In addressing the overall research aims, the micro level narratives of accessible housing illuminated what Thomas (1999) referred to as lived experiences and the interplays of impairment affects within disablement in Scotland and Norway. In order to access appropriate accessible housing, participants required autonomy over housing related decisions. Research participants reported divergent pathways into accessible housing for GCIL service users and Uloba co-owners. Scottish participants discussed how austerity measures had impacted upon them obtaining accessible social housing and/or maintaining independent living at home. Contrastingly, disabled people in Norway were more likely to own their own home. However, they shared the challenges surrounding attitudinal support to live independently, as well as issues connected with the affordability of housing related costs.

There was a consensus in both countries that accessible housing was one component of a joined-up approach towards independent living (French and Swain, 2008); an accessible property needed to be embedded within an accessible external environment and have accessible public transport links, facilities and amenities. This research did not include the views or lived experiences of disablement from disabled people with no contact with GCIL or Uloba. A comparison between the role of peer support from their perspectives and of those in the existing data set may have revealed to what extent peer support facilitated access to accessible housing or what happens if peer support is lacking.

The narratives of accessible housing at a meso level uncovered governance structures that have been adopted by GCIL and Uloba that enhanced disabled people's access to independent living. The main way that GCIL and Uloba utilised peer support was to facilitate access to accessible housing through joint working to explore financial avenues to obtain or maintain housing options. There were divergent resource capacities between GCIL and Uloba to participate in the provision of housing services. On the one hand, GCIL pursued competitive funding streams to operate a housing advisory service, while on the other hand, Uloba concentrated on organisational resources and on a personal assistance model that directed disabled house seekers to a Norwegian State Housing Bank, the Husbanken, to receive appropriate financial support. Both GCIL and Uloba recognised the need to adopt a joined up approach towards housing services. At the time of field work in 2012, GCIL provided employment opportunities through various positive action schemes, while Uloba sought to boost the employment opportunities for disabled people within the organisation and actively supported improvements to the Norwegian educational system.

At a macro (national, decision-making) level, research participants' narratives around accessible housing in Scotland and Norway demonstrated what Thomas (1999) referred to as structural challenges for disabled people's access to independent living. Across the 12 Pillars of Independent Living neither country exhibited disabled people's rights to accessible housing as advocated by Reid Howie Associates (2007); Wessel (1998) and Ytrehus (2011). Collective efforts and campaigns among disabled people had resulted in policy change, for instance, the

2011 Housing Strategy (Scottish Government, 2011) and the Anti-Discrimination and Accessibility Act of 2009.

There were concerns raised from research participants that housing policy lacked a strategic coordination with other areas of independent living (French and Swain, 2008). For example, the online survey respondents in both countries highlighted that a tenure-neutral approach needed to be adopted in the future. In particular, housing representatives from the online survey highlighted the potential knowledge transfer capacities of social landlords to inform the procedures and policies surrounding accessible housing. Regardless of tenure, the respondents pointed out that private construction companies and local authority planning departments were responsible for all property design standards and housing developments. Similarly, aspects such as funding for adaptations or the building regulations for universal design standard tended to encounter different procedures or omissions from the private sector, in particular.

The following chapter goes on to explore the area of personal assistance. This forms another of the 12 Pillars of Independent Living (Spectrum, 2016). As with Chapter 4 on peer support and Chapter 5 on accessible housing, Chapter 6 will utilise a social relational model (Thomas, 1999) to explore the structural factors and lived experiences of personal assistance.

# Chapter 6. Personal Assistance

## 6.0 Introduction

Chapter 6 presents findings on the third key theme emerging from the data, which was around the importance of personal assistance to independent living for disabled people. The term personal assistance broadly denotes the support provided for disabled people by people working directly for the disabled person in order that they can access everyday tasks within the home and work environments (Guldvik, 2003; Rummery and Fine, 2012). This chapter is divided into four sections and presents macro (national policy), meso (organisational) and micro (agency) level narratives around the area of personal assistance. An important aspect that should be noted for the Scotland data is that interviews took place during a period of policy change in relation to Self-directed Support. Fieldwork was carried out in 2012, preceding implementation of the Social Care (Self-directed Support) (Scotland) Act 2013. However Self-directed Support was available prior to this act through the Community Care and Health (Scotland) Act 2002 which placed a duty on local authorities to offer direct cash payments to eligible people to enable them to arrange and buy their own community and personal care. Many of the discussions touched upon interviewees' apprehensions or desires concerning Scotland's approach towards Self-directed Support, as set out in the national Self-directed Support Strategy (2010), and the upcoming policy change in relation to Self-directed Support. Consequently the interviews captured data from a specific snapshot in time.

Pressure from the Association of Directors of Social work and the Disabled People's Movement in Scotland culminated in the Social Care (Self-directed Support) (Scotland) Act 2013, which states that local authorities in Scotland must give disabled people four choices: direct payments, directly support disabled people's social care needs, let the local authority direct their support or a combination of the previous three options.

The first section, Macro Narratives of Personal Assistance, focuses upon the national policy arena in Scotland and Norway. Discussions explored to what extent

national policies have enshrined disabled people's rights to personal assistance, the arbitrary nature of eligibility based upon criteria of impairment severity and whether disabled people's income should contribute towards personal assistance services.

The second section, Meso Narratives of Personal Assistance, highlights the important role of user training and personal assistant training for the empowerment of disabled people, and that effective personal assistance delivery requires appropriate levels of resources. The third section, Micro Narratives of Personal Assistance, uncovers lived experiences of the personal assistant recruitment processes.

The final section, entitled Significant Findings of Personal Assistance, examines to what extent the data from this study supports or challenges findings from prior research and the wider literature discussed in Chapter 2. For example, participants' narratives around personal assistance demonstrated application of the social relational model of disability (Thomas, 1999) and provided an insight into the multi-strata interactions of disabled people's access to independent living. The underlying theme of the importance of peer support is also explored again for interconnections with the area of personal assistance. The chapter closes with an overview of how far the data addresses the research questions, before introducing the main discussion chapter which follows.

As outlined in Chapter 3, pseudonyms are used for the organisational case study participants to try to protect interviewees' identities within a close community. Survey responses are anonymised, unless respondents waived anonymity in order to openly support particular views or issues.

## 6.1 Macro Narratives of Personal Assistance

The macro narratives from research participants highlighted two sub-themes. Disabled People's Rights to Personal Assistance explored to what extent the national policy landscapes in Scotland and Norway facilitate access to personal assistance services. Closely linked to this, Eligibility and Funding examined national and local resource allocation decisions based upon criteria of individuals'

impairment severity. Participants reflected upon whether there should be societal expectations that disabled people contribute part of their income towards personal assistance costs.

### 6.1.1 Disabled People's Rights to Personal Assistance

The macro narratives from research participants revealed that although in both Scotland and Norway disabled people may have a right, as defined in Chapter 2, to be assessed for personal assistance, the powers of decision-making lie with meso level care providers. As Wallace (2009) noted, governance is a useful concept through which to explore the eligibility criteria behind, and the delivery process of, welfare resources such as personal assistance. This can take formal and informal forms that are operationalised through state assumptions around disabled people's civic engagement and expectations for self-governance of disabled citizens (Morris, 2005). The research participants' macro narratives demonstrated the interplay between regulatory and distributive policies (Hvinden and Halvorsen, 2003) that control access to personal assistance in Scotland and Norway.

The aims of regulatory policies are to remove barriers within society so that disabled people have access to equal opportunities in all areas of life (Hvinden and Halvorsen, 2003). In Scotland, key expert Angel discussed the introduction of the first significant regulatory policy that addressed the area of personal assistance: the Community Care (Direct Payments) Act (1996). Angel noted that this policy was implemented due to pressure from the Disabled People's Movement, whereby disabled activists campaigned to have disabled people's voices included within the policy making process in the area of personal assistance (Roulstone and Prideaux, 2012). Disabled activists aimed to change legislation in order that disabled people were enabled to purchase their personal assistance.

Angel thought that the GCIL placed too much emphasis upon a disabled person controlling all aspects of their care delivery. For instance, Angel drew attention to the range of care delivery options available to disabled people, for instance Direct payments are only one of four options available under Self-directed Support. The other three options are that service user designs their care package but the council

hold the money and arrange delivery of care, the service user agrees for the council to choose the type/amount of care needed and arrange delivery of the care, and the service user can decide upon a mix of the previous options to tailor a care package/delivery of care to their preference. Another example of personal assistance delivery that Angel discussed was In Control, a social enterprise set up by Simon Duffy in 2003 to assist people with learning difficulties to manage personal assistance services. In Control have a spectrum of care delivery options that give varying degrees of responsibility for the service user (Duffy et al., 2010).

Contrastingly, senior Uloba manager Bronnil asserted that, in their opinion, Norway was fortunate to have the second best personal assistance scheme in Europe, coupled with a privileged resource-rich infrastructure. The best personal assistance scheme, according to Bronnil, belonged to Sweden. As described by Roulstone and Hwang's (2015) case study of STIL Centre for Inclusive Living in Sweden, personal assistance for disabled people is a right within Swedish law for those in receipt of twenty hours or more care. A few Uloba participants commented that this provided a bench mark which they were aiming to achieve and surpass.

In Norway, the Municipal Health Services Act of 1982 first identified that the Norwegian municipalities were responsible for long-term care services. This devolved approach to governance was to reflect that each area could customise services that suited local needs, local conditions and local political orientations. In the year 2000, user-controlled personal assistance became legalised under § 4-2 of the Social Services Act (2000). However, Asle (Uloba guarantor) explained that after the year 2000 Uloba campaigned for further policy change in order to increase access to personal assistance for people with cognitive impairments.

Asle became involved with Uloba because both of their daughters required personal assistance services. Around the year 2000, Asle explained that Norwegian law excluded disabled people who were unable to organise their own affairs due to having personal assistance. This significantly impacted upon those with cognitive impairments. Asle worked at Uloba during that time and was involved with campaigning for policy change. In 2005, they were successful and the law

incorporated the role of guardianship, normally by a family member, to enable everybody to access personal assistance.

Nearly all research participants in Norway remarked that they would like the State to introduce access to personal assistance as a right for all disabled people. As noted by the Independent Living Institute's report during the 2009 election, the Labour party, currently in opposition, had supported a bill to implement user-control over choice of personal assistance provider (Westberg, 2011). However, they retracted this and supported the social expectation that disabled people should be viewed as passive recipients of care with user-control linked to home-help and personal assistance to medical care services.

Norwegian survey respondents indicated that personal assistance should be a right for disabled people. For instance, an anonymous respondent asserted that:

> *"User-controlled personal assistance (Brukerstyrt Personlig Assistanse) is not a nation-wide regulation, with varying services between different municipalities (and councils)."*

Another anonymous participant noted that the legislative measures which are currently in place were often ignored by those legally obliged to comply, and that regulations and policies were continually tightened or removed. In concurrence, the representative from Optimal Assistance (AS) remarked that existing impediments were:

> *"… for example, exemptions in relation to legislation, municipal autonomy (as in council may not need to follow state regulations), lack of a legal right to Brukerstyrt Personlig Assistanse [user-controlled personal assistance], lack of knowledge among civil servants and politicians, IPLOS (a central, governmental health register with information relevant to the assessment of assistance and service needs)."*

At a macro (policy making) level in both countries, research participants described that there existed gaps between the political rhetoric surrounding disabled people's rights to personal assistance or access to independent living, and practice. As Bickenbach and Cooper (2003) have proposed, there is scope to adopt a holistic

policy approach towards independent living, including personal assistance, and to ensure that policy is informed by a rigorous and relevant evidence-base. For instance, they put forward that societies should examine disabled people's access to independent living in terms of participation indicators where citizen outcomes can be monitored.

### 6.1.2 Eligibility and Funding

As discussed in Chapter 2, Hvinden and Halvorsen (2003) have outlined the challenges surrounding issues of eligibility and funding faced by distributive policies. For example, the rising costs of disability related benefits across Europe (Stone, 1984) supported the use of what Bickenbach and Cooper (2003) referred to as arbitrary and artificial eligibility thresholds. From a political and economic perspective, this justified macro level decision making from the state as to which welfare recipients should be categorised as deserving or undeserving.

At the time of fieldwork in 2012, the rising costs of disability related benefits remained a concern for both the UK and Norwegian governments. According to figures from Eurostat (2018), since 2010 members of the European Union (this includes the UK but not Norway) show stable expenditure on social protection, this denotes disability related benefits. Figures show that the UK allocated 6% of their expenditure towards disability benefits. This places the UK among the EU countries with the lowest expenditure compared to other such as Denmark that allocate approx. 12% towards disability benefits.

Støve (2015) explains that the public social security system in Norway is called the National Insurance Scheme (NIS). This scheme covers people aged 16-66 years and includes benefits for retirement, sickness, unemployment insurance, health insurance, and long-term unemployed due to health grounds. From age 67 years, these benefit recipients transfer to a retirement pension. Hans outlined that in January 2015 a new disability related benefit was introduced. This aimed to provide greater flexibility than the previous system for disabled people in periods of work. The high rate of disability related benefits are a concern for the State welfare system as discussed by Bratberg et al (2015) who reported that in 2011, 9,5%of the working age population (18-66 years) were in receipt of disability benefits.

A divergence was apparent in relation to research participants' discussions of eligibility for resources, such as personal assistance. One of the weaknesses of this comparative study was the inability to attain interviews with GCIL service users with sensory or cognitive impairments. However, the literature (see Bickenbach and Cooper, 2003) indicated that the benefit system in the UK was structured on a scale of impairment severity with intense competition amongst recipients for scarce resources. The GCIL service users who participated in the study all had severe locomotion related impairments and were in receipt of the higher rate of care under the Disability Living Allowance. This component acted as criteria to trigger an application for personal assistance through Self-directed Support.

In the Scottish survey results, respondents also identified that the inconsistent approach towards personal assistance and social care mentioned above was an impediment for disabled people's access to independent living. Respondents first drew attention to the ways that the Adults with Incapacity (Scotland) Act 2000 and the Adult Support and Protection Act 2007 were open to interpretation; they produce a disjointed approach towards implementation and, according to the first respondent, can result in discrimination if carried out in conjunction with cost-cutting measures. The second respondent reflected that current community care services exhibited variable eligibility criteria. The third survey participant echoed this view:

> *"For example, in order to get a blue badge for disabled parking local authorities assess you on the same criteria as for high rate disability living allowance. This is highly unfair and subjective and not everyone who would benefit from one would get it due to these policies. Furthermore, disability can mean and affect persons in such a diverse number of ways and sometimes if a person doesn't tick the box they may be actually disadvantaged into accessing services which would allow them to live independently."*

GCIL service user Pip asserted that the austerity measures towards welfare reform since the Conservative-Liberal Democrat coalition UK government came to power in 2010 had resulted in an emphasis upon basic needs assessments to determine

an individuals those most in need. These assessments identified the minimum support required to perform essential tasks, including getting out of bed, washing and eating, rather than to enhance wellbeing through, for example, socialising or participating in sport activities. Life, Pip argued, was also about quality of living. When talking about the decisions made by local authorities around social care budgets, Pip had heard stories about the implementation of welfare reforms leading to many disabled people being unable to participate fully in society and becoming what Pip termed prisoners in their own homes. Pip was also aware that the social work department had voiced concerns that if Pip required 24 hour care in the future, there may not be money available to enable this to happen at Pip's home.

GCIL senior manager Sam voiced several improvements that they felt could be implemented in the way in which the personal assistance models delivered services in Scotland. Firstly, Sam explained, the Path Provider model assumed that service-providers would maintain an objective impartial approach while assisting service users to complete the initial needs assessment questionnaire. However, social workers were often charged with guarding scarce resources and, in particular, vulnerable service users may have needs curtailed as a result. Sam explained that such concerns led to the setting up of surgeries. Service users and their families can receive help or advice with the whole process and, where appropriate, be directed to advocacy support.

Norway's personal assistance model was a needs-led approach with Norwegian municipalities in possession of the decision making around the definitions of disabled people's needs. For example, regional leader Skylar described their experience of applying for personal assistance as an individual with a visual impairment. At first, she received seven hours of personal assistance a week and, after a nine month appeal, this was increased to twenty hours per week. She had three personal assistants and one for emergency cover. Uloba provided invaluable support throughout the appeal process since the impairment specific organisation that she was associated with argued that personal assistance would make her look more dependent. Although Skylar had a guide dog to aid with mobility, in line with the social relational model of disability, a personal assistant enabled her to address remaining barriers such as, navigating new environments. Additionally, they helped

her to access inaccessible services, do gardening and helped with organising correspondence.

A couple of participants touched upon the issue of whether disabled people should contribute financially towards their personal assistance costs. The view expressed in Scotland mirrored an approach of free personal care for all within a liberal society, while the view expressed in Norway reflected an egalitarian means-tested system (Esping-Andersen, 1990). In relation to the extent of care charges in Scotland, the Money Advice Service provides an explanation on their website. They outline that a means test considers:

- your regular income – such as pensions, benefits or earnings
- your capital – such as cash savings and investments, land and property (including overseas property), and business assets (Money Advice Service, 2018)

The Money Advice Service continue that in Scotland, the threshold that a person's income and assets must not exceed is £26.500. Local authorities may expect an individual to still contribute towards some of the care costs even if their income/asset fall below the threshold. A person's home is not included as capital if care is received at home and in Scotland there is a Personal Care Contribution component paid to 65 year olds and over. Care charges vary across local authorities and the exact amounts affecting particular individuals will depend on where they live. For example, GCIL senior manager Leigh was opposed to disabled people contributing financially to their personal assistance:

> **Leigh:** *"So as a person with a spinal-cord injury who uses a power-wheelchair, yes I occasionally find that I need help getting up in the morning, to get washed, get dressed and get ready for work. And actually, at the moment even though I run an organisation that provides support through self-direct support, I use the local authority for my support because I only need half an hour every morning and I find that they do it, mostly, fairly well. But not always, and they charge me a lot of money for it and I don't think that I should have to pay for it. So those are the kinds of things that piss me off as a disabled person."*

This viewpoint was included in the Scottish survey results, provided by the Inclusion Scotland's Policy and Engagement Officer. This representative concurred that charging for social and personal care was a tax on disability. This undermined the ethos of independent living through the removal of a proportion of disabled people's income for council services. They pointed out that other public services, such as libraries, were free. Therefore, they concluded that the need to divert income towards assistance to get out of bed or go to the toilet hindered disabled people's full participation within communities and society.

Conversely, Uloba founder Kris endorsed a means-tested approach especially for disabled people in paid employment. Kris explained the process in Norway, whereby the employment department of the Norwegian government gauge how much a disabled person should contribute towards their personal assistance:

> **Kris:** *"We have the welfare state so the local government are allowed to take co-payments. But co-payment for me on 35 hours per week on average is 30,000K per year. It is a lot of money, but if I didn't have a good income then I would hardly pay anything at all. I think it is okay but there are a lot of people who want to fight the co-payment instead of fighting a good life. They want everything free."*

The above discussions surrounding whether personal care costs should be met by tax payers in general or include a means-tested threshold whereby disabled people are expected to contribute, connects with debates around the introduction of a potential unconditional basic income (Bay and Pedersen, 2003). As Andersson (2000) outlined, such an approach is a logical step, particularly in Norway. At the time of the fieldwork in 2012, the social security system in Norway adopted a proportional payroll taxation model – a blend of the Danish flat rate and Swedish income based approaches. Uloba founder Kris's viewpoint that disabled people in work should contribute towards personal assistance costs corroborates Bay and Pedersen's (2003) conclusion that Norway's progression to a flat rate framework for social security is mitigated by a societal value system that centralises the role of the work ethic to underpin the Norwegian sense of citizenship.

### *6.1.3 Summary*

To summarise, the macro (national policy) level narratives from research participants highlighted discussions around regulatory and distributive policies of personal assistance (Hvinden and Halvorsen, 2003). Firstly, many examined to what extent national regulatory policies enshrined disabled people's rights to personal assistance. Both countries have experienced policy developments in the area of personal assistance through pressure from the Independent Living Movement. However, according to Bickenbach and Cooper (2003), a holistic policy approach towards enhancing disabled people's access to independent living will require adoption of evidence-based policies and the use of measurable participation indicators.

Closely linked to this theme, research participants shared their views of the eligibility and funding arrangements in Scotland and Norway. Both encountered restrictions around who can receive personal assistance based upon severity of impairment or amount of support required. This supported Bickenbach and Cooper's (2003) assertion that policies are often based on arbitrary or artificial criteria that seek to justify a specific political or economic perspective. In conjunction with this issue was the debate around a proposed unconditional basic wage (Bay and Pedersen, 2003). The Scottish participants supported free personal assistance in line with a liberal welfare perspective, whilst the Norwegian participants supported a means-tested contribution scheme that echoed Norway's social democratic model and work ethic (Andersson, 2000; Esping-Andersen, 1990).

## 6.2 Meso Narratives of Personal Assistance

Meso (organisational) level narratives from research participants explored two sub-themes. User Training and Personal Assistant Training emerged as a key method through which GCIL and Uloba empowered disabled people. Both GCIL and Uloba participants reflected upon the necessity to have appropriate levels of resources in place that could deliver effective person-centred personal assistance. User led personal assistance services highlighted how user led organisations, such as GCIL and Uloba, are better placed to utilise resources. For example, there are

challenges in both countries for disabled people who wish to go on holiday or participate in activities outwith the established remit of routine personal assistance support packages.

### 6.2.1 User Training and Personal Assistant Training

Both GCIL and Uloba delivered personal assistance services for disabled people but in slightly different ways and in different contexts. Research participants highlighted that user training was a key method of empowerment. Shakespeare (1998) has outlined that empowerment denotes enabling disabled people to control and make choices over everyday life decisions, not concentrating upon how many tasks an individual can perform. Senior Uloba manager Bronnil summarised such sentiments when they stated that Uloba's goal for user training was:

> **Bronnil:** *"… primarily about changing inside your own head. You turn the roles upside down. It's not about the assistant who is making sure that you have a good day. It is not about that. It is about you. You are in charge of the assistance so it's your choice to make sure of what and when, that is a complete change of attitude because you are the provider of the leadership, you are the provider of the assistance and the boss of everything. You are in charge and then when something happens, then you can straighten out or be a grown up human being and say that I am in charge of my life."*

In 2012, at the time of fieldwork, GCIL had six advisors to assist with their personal assistance service. This might mean, as senior GCIL manager Sam described, that service users would have a direct payment account or the new individual budget. They would be allocated a named GCIL case worker who provided advice on the use of funding, how to access funding, set up a care package, train individuals to become an employer of personal assistants and how to recruit potential personal assistants.

GCIL guidance and support was welcomed by all of the service user research participants. Ali remarked that they were appreciative of their advisor's initiatives to arrange dates, at least four times a year, where the focus was upon completion of Ali's social work returns and how care-support funds were spent. As Pip

commented, service users were perceived as independent, small employers. Therefore, an important responsibility was to learn their legal rights under this role as well as those of their employees.

The homes of GCIL service users were viewed as work environments. Appropriate work conditions were required and any necessary health and safety precautions had to be put in place for everybody involved. Service users had to ensure that they had insurance to cover employees and themselves in case of accidents or situations where their personal assistant may sue, for example, for an unfair dismissal. As Pip concluded, it was all about learning entitlements and what you, as the employer, could and could not do.

Since January 2012, legislative changes had increased access for disabled people to Uloba's personal assistance services. As outlined in the literature review (Chapter 2), Uloba delivered a sole personal assistance model to co-owners based upon a service user cooperative model (Co-operatives UK, 2004, cited in Glasby and Taylor, 2006). Bronnil, senior Uloba manager, outlined that this new bylaw had recently enabled anybody who self-identified as disabled to become a co-owner of Uloba. Previously, people had used the organisation as their personal assistance service-provider. Several case study participants envisage that individuals who do not require personal assistance will need to contribute a specific amount of financial or practical support towards Uloba. For example, some speculated that this might take the form of fundraising. Bronnil continued that new co-owners are assigned a named peer counsellor. The goal was to train the new co-owners to become a work leader: an informed and competent controller of their personal assistance.

The finance stream for personal assistance in Norway comes from one main source, the Norwegian State. Espen, senior Uloba manager, explained that co-owners join Uloba for a 1,000 kroner (KR) fee. This is returned when the co-owner leaves. Co-owners have two accounts with Uloba: one for their payroll activities and a second as a contingency pot. The latter is used towards paying for pieces of equipment such as a personal assistant's mobiles or putting money towards extra wages while the co-owner is on holiday. Espen continued that personal assistants'

wages are above the minimum wage and in line with payments to nurses. On average, this is 150 KR per hour and increases with a person's age and experience. Therefore, a very experienced personal assistant could work for 200 KR per hour. Over time, evenings and holiday pay can add 40%. Therefore, personal assistants can progress through attainment of higher increments based upon past experience, age and length of job engagement.

The provision of good quality training for personal assistants was a strong theme throughout research participants' narratives in both countries. As GCIL senior manager Leigh discussed, this topic illuminated differing goals between the Independent Living Movement and the carers' lobby in Scotland. Senior GCIL manager Sam expanded that the Independent Living Movement was against the over-regulation of personal assistants. This could produce standardisation of practices, such as disposing of items in the fridge that were past their sell-by-dates without consulting the service user.

GCIL service user Ali's experience of personal assistance reflected such comments. Ali's personal assistance spans 60-70 hours per week with a flexible rota. Tasks switch between cleaning floors, getting into bed and the toilet and assistance with reading mail. It has been easy to lose autonomy over the basic standard of cleanliness around the house. Ali stated, "...*my house is the cleanest it's ever been in my life!*"

The training and retention of personal assistants in the UK has been affected by depressed wages, which has left personal assistants vulnerable to exploitation or subject to stigmatisation as low value members within society (Rummery and Fine, 2012). Rummery and Fine (2012) have also commented that there has not, as yet, been a systematic body of evidence to compare the policy equity outcomes for recipients of care across different welfare regimes. They call for a citizenship approach to care. They asserted that without social participation, choice and control can result in an environment of enforced gratitude from recipients for services that may not necessarily meet all their needs. A reframing of care within a citizenship discourse, as opposed to that of markets, would establish its role as

a means of self-determination and social participation for both carers and the cared-for.

Sam (GCIL senior manager) recognised the challenges that GCIL faced when promoting personal assistance as a financially viable and rewarding career choice for individuals. Although GCIL can do little to address the low wage rates for personal assistants set by national and local government, Sam outlined plans to tackle personal assistant training that would develop a high level of support. At the time of the fieldwork, GCIL was in the process of establishing a new training course for potential personal assistants at a local college in Glasgow. This would include first aid, food hygiene and moving and assisting training. The latter had originally been called moving and handling; Sam had pointed out that disabled people do not like to be handled and that the word assisting reflected providing support in a respectful and empowering manner. Part of the training included introducing people to the social model of disability, the ways that personal assistants can provide control for disabled people and the importance of non-discriminatory language. The course can be funded via Individual Learning Accounts (ILA) run by the Scottish Government.

At Uloba, the working conditions and quality of training for personal assistants are also important aspects of Uloba's personal assistance model. Aren (former Uloba regional leader) explained that their organisation had lost 180 co-owners from fourteen municipalities in the West of Norway due to dissatisfaction with the treatment of personal assistants. Norway, Aren said, has a Norwegian Standard that came into law in 2014. These fourteen municipalities refused to spend money on personal assistance training, peer support services for co-owners or advice. Thus, many co-owners found themselves in the position like Asle. Asle's daughter received support all day and night from the municipality. Asle had encountered a significant difference with Uloba as their service-provider because most of the administrative chores were performed for the family. Under the new system, the payment schedule was less flexible and more administratively demanding, and Asle commented that:

**Asle:** *"The main differences are that you have more money to pay for the assistance. As before we used to go away in Easter time and we're not able to do that now because we don't have any money to pay for the assistance. And they don't have any money to pay for going to the conference."*

Research participants in both countries expressed challenges with disabled people's access to personal assistance due to resource constraints. In the UK, it was noted that the uptake of direct payments since 1996 had been slow due to several issues, including a lack of funding, lack of clarity in government guidelines, professional domination of services, front-line staff reluctance to implement the change in welfare policy, negative assumptions concerning the capabilities of applicants and a lack of information and support for potential users (Duffy, 2010; Pearson, 2004; Pearson, 2000; Priestly et al., 1999). GCIL senior manager Leigh, for instance, highlighted many of these issues. They described that disabled individuals are often omitted from the decision-making process; decisions are often made at a local level and by professional gatekeepers. This affects disabled people's life choices and ability to react spontaneously since there lacks universal entitlement:

**Leigh:** *"Whether you could take a package of support from one local authority area to another depends on a whole range of issues. Those issues include the eligibility criteria in one area compared to another can be different, the fact that you can't get a theoretical assessment. If I want to move to Aberdeen I will have a great degree of difficulty finding out what I would be entitled to before moving to Aberdeen, by which time it would be too late; I might realise that I wouldn't be able to manage and take up this opportunity of a job or whatever if I move to Aberdeen. The third factor is community care charges which are different."*

Another GCIL senior manager, Chris, highlighted the ways in which proposed welfare cuts at the time of fieldwork would have a negative impact upon disabled people's control over their personal assistance. One of these measures was the introduction of the bedroom tax (officially withdrawal of housing benefit subsidy from defined spare bedrooms from 1st January 2014). Chris asserted that many

disabled people required a bigger house to accommodate a personal assistant to stay overnight or to store disability related equipment. These apprehensions were corroborated by early analysis of this element of welfare reform. Wilcox (2014) found that disabled people make up two thirds of those affected by the policy. Despite local availability of discretionary payments (Powers, 2013), many faced the challenge of downsizing in a climate where there was a general lack of one-bedroom properties within the social housing stock (Wilcox, 2014), coupled with a shortage of accessible properties (Inclusion Scotland, 2008).

Furthermore, Chris continued that proposed welfare reform would also impact upon disability benefits. The Disability Living Allowance was due to be phased out by 2015 and replaced by Personal Independence Plans. Chris explained the Disabled People's Movement had lobbied hard for the government to implement a self-assessment process. This unfortunately would be abandoned as the benefit system reverts to a medical diagnosis approach, which in Chris' opinion was a disappointment to be taking twenty steps back in terms of disabled people's empowerment. Thus, the medical model (Drake, 1999) was being engaged to judge applicants via a thirty minute consultation by 3rd party assessors who may have specific targets to meet in relation to welfare allocation.

As Askheim (2008) commented, there has been cross-political support for welfare reform measures in the UK. The notion of Self-directed Support appeals to a market-based consumer stance or to a radical civil rights perspective. Powers et al. (2014) proposed in their report about the spare-room subsidy withdrawal that, in general, eligibility criteria for benefits were tightening under austerity measures. All GCIL service users voiced concerns about the upcoming redistribution of welfare resources. For example, GCIL service user Alex noted that their living costs, such as rent, payment to the social work agency (for personal assistance service) and council tax were all increasing alongside cuts in disability related benefits.

Senior GCIL manager Joe voiced concerns about the way political and social rhetoric were questioning disabled people's rights to welfare support for independent living. Joe exclaimed that:

> **Joe:** *"The current welfare reforms are basically the most successful demonization of disabled people you've ever seen. Disabled people are a bunch of wasters who are at it and draining the country of money; that's how disabled people are being portrayed and there's ... I don't know what the latest hate crimes are, but I'm sure it's had an influence."*

Sam (GCIL senior manager) also drew attention to other financial ventures Scotland had on the horizon at the time of fieldwork in 2012, including the 2014 Commonwealth Games which may divert scarce resources into specific national level priorities. Sam exclaimed that how could society justify financing the construction of a velodrome which may not be used very much after the games. In contrast, disabled people were being told that no resources were available to cover even their basic care needs. Sam continued that people appeared willing to say to disabled people:

> **Sam:** *"Well if you need 24 hour care we can't keep you in your own home so you'll go into residential care. And the problem is they don't openly say some of these things, they just gradually happen to people, cause the support they need's getting eroded."*

In Norway, concern was also voiced about the reduction to personal assistance budgets. However, it should be noted that these apprehensions were not to the same extent as amongst the Scottish participants. Christensen and Pilling (2014) asserted that a strong social-democratic country like Norway should demonstrate a well-developed system that connected citizenship rights with state provision of necessary services. However, their examination of personal assistance in Norway illustrated that this was not the case. As mentioned earlier, disabled people in Norway have a right to personal assistance but under current legislation it is the Norwegian municipalities who determine whether a person is eligible for personal assistance and the amount of support that the individual requires.

GCIL service users and Uloba co-owners all faced the same financial constraints associated with personal assistance services during holidays. Neither country had holiday nor rest periods automatically attached to their welfare entitlements. For example, GCIL service user Jessie drew attention to the fact that as well as their

holiday costs they would need to afford the personal assistant's wages, feed them, provide accommodation and cover their travel expenses. This might apply to several employees if the support required, as with Jessie, relied upon multiple assistants.

Fellow GCIL service user Pip recounted that with the Self-directed Support approach, it was possible to negotiate with social work to cover holiday costs. They recognised that Pip had not been for a holiday in a while and were prepared to help to source and finance specialist equipment such as a hoist at the holiday venue. It was not about going off to climb Mount Everest Pip explained, "*but enjoying self-time on perhaps a cruise*". Norway co-owner Per similarly imparted that their family had decided to sell the log cabin retreat they had in order to fund personal assistance during a cruise that included going to the Russian border. Although, they required a separate ship cabin for the personal assistant and needed to cover, what Per referred to as, an explosion of personal assistance hours. The narratives from Pip and Per demonstrate the subjective and inconsistent approaches towards the definition of need in both countries; leisure activities tending to be deemed desirable, rather than essential.

Ellis et al. (1999) have pointed out that one of the main issues affecting the provision of personal assistance across European countries was the rationing of social security benefits. This, Ellis et al. (1999) argued, was not a new phenomenon and that society's social care needs and demands tended to always outstrip supply. Therefore, an effective personal assistance model relied upon appropriate resources for delivery. The lack of appropriate resources for Centres for Inclusive Living has been discussed, for example, by Marian Barnes (2007). Barnes had pointed out that Centres for Inclusive Living can be financially tied into participating in actions or the political agenda of the state. Additionally, disabled people, Barnes argued, lacked the necessary power to influence national and local decision making around resource distribution. This was mainly due to a significant under-representation of disabled people employed within senior positions in organisations within the charity sector. Attempts to address this issue had been met with scepticism and charges of tokenism (Oliver and Barnes, 2012).

### 6.2.2 User Led Personal Assistance Services

Scottish research participants discussed the ways that GCIL, as a user led organisation, had provided guidance or advice related to personal assistance. For example, GCIL service user Alex found direct payments too complicated. The use of direct payments involved time and organisational skills to maintain personal assistance as an employer. Alex explained that the use of an agency suited their situation:

> **Alex:** *"You've to use the money to employ an agency like I'm doing at the moment, but then what's the point of that? I'm already getting an agency and the only reason I would go over to Self-directed Support would mean they employ people that I interviewed and I wanted. But then you have to have kind of tax arrangements and you'd have to have a separate bank account and three or four standbys in case one is on holiday or phones in sick, whereas the agency just does that for you."*

However, Alex outlined that the use of an agency also entailed inflexibility. Examples included a lack of spontaneity regarding going for a drink after work or the need to forgo a long lie, especially when the agency was short staffed. This narrative reflected concerns voiced by authors such as Russell (1998), Young and Quibell (2000) and O'Brien (1999 and 2001) who questioned whether notions of choice, individual budgets and the person-centred approach associated with, for instance, Self-directed Support equated with empowerment for disabled people. Self-directed Support has been viewed as a method to implement austerity measures that impact upon vulnerable groups within society and that perpetuate competition for scarce resources among recipients (Clare and Cox, 2003; Solvang et al., 2003; Spandler, 2004). Effective delivery also relied upon the existence of allies for independent living within front-line delivery or policy-making (O'Brien, 1999).

GCIL service user Pip reported satisfaction with their use of Self-directed Support. Since the fieldwork for this research took place prior to the Self-directed Support (Scotland) Act (2013), it is likely that Pip was participating in a pilot scheme, such as the pilot study of Individual Budgets in North Lanarkshire (Etherington et al,

2009). However, this was not confirmed by Pip, apart from disclosing that their support arrangements had changed recently and Pip did not disclose the local authority area in which they lived (it could be Glasgow or North Lanarkshire as they are neighbour each other). Pip explained that instead of a direct payment, a monthly payment arrived from the council which went towards the personal assistant's wages, insurance and contingency pot. GCIL, or a designated care manager at the social work department, was on-hand if Pip felt that extra help was required to sort out these arrangements. Pip also commented that the council were aware from Pip's needs assessment that additional hours were required in practice but, due to restrictions in available money were unable to finance Pip's full package of care.

Scottish survey respondents identified user-control of services and support as an important facilitator for disabled people's access to independent living. It was closely followed by calls for each local authority to become an independent living council. Inclusion Scotland's Policy and Engagement officer provided a summary when they wrote that:

> *"For local councils to become independent living local authorities, and for all national and local policies that might impact on this right to include the independent living principles and human rights. Similarly, we would like to see equality impact assessments and equality outcomes using these principles as a measure of their facilitation of IL. We would also hope that these principles are also actively promoted as part of work done by such authorities so that awareness is raised and disabled people feel confident to draw on the principles to express their rights."*

GCIL is operating in an environment where there is a lack of Centres for Inclusive Living within each locality. According to the Social Care Institute of Excellence (2009), a pledge was made by the UK government in the Prime Minister's Strategy Unit report, Improving the Life Chances of Disabled People (2005) and re-stated in the 2007 Putting People First policy document to improve this. The Office of Disability issues (2011) depicted the benefits CILs make to disabled people's access to independent living and the advantages for service providers.

In Norway, Uloba founders were at the forefront of a personal assistance pilot scheme during the early 1990s under the Norwegian Association of Disabled People (Independent Living Institute, 2011). The development of Uloba had increased user led delivery of personal assistance for disabled people across Norway, but Norwegian municipalities at the time of fieldwork in 2012 dominated the provision of personal assistance. The Municipal Health and Social Care Act (2011) stipulated that although municipalities are obliged to secure quality services, they do not necessarily need to act as service-provider. Christensen and Pilling (2014) pointed out that a significantly low level of municipal services are delivered by other providers: only 8.1 per cent of the sector's services are purchased from private actors (SSB, 2012). Gammelsæther (2006) observed that municipalities were more likely to engage other contractors in relation to monitoring of performance.

All the disabled research participants in receipt of personal assistance outlined that they had needed to challenge initial municipality decisions. An Uloba founder Kirby, for example, was confused by their municipality's calculations of the designated amount of personal assistance hours. Kirby was approved 75.3 hours per week but with no clarification on whether the point three equated to twenty minutes.

These viewpoints were echoed by the Norwegian survey respondents. Some respondents wrote that localised decision-making amongst Norwegian municipalities created impediments for disabled people's access to independent living. For instance, one anonymous participant commented that local decision making can act as a hindrance and that:

> *"When it is up to each municipality to decide what is in your best interest, situations will arise that prevent individuals in controlling their own lives."*

Norwegian survey respondents also reported that professionals tended to dominate service delivery to disabled people and that there was a need for greater user led control. The Communications Consultant for the Children's Ombudsman (Barneombudet) shared that he was looking forward to the future when their daughter would enter a person-centred personal support environment. As he explained:

> *"My daughter will be moving to an apartment with associated services that will give her the opportunity for active leisure, and not be in a service programme that is standardised and has a staff rotation that prevents her from going to the movies, concerts and events when they might be. She is so mentally handicapped that work is not an option, but she will attend and enrol in a good day activity programme."*

At the time of this study's fieldwork in 2012, only a quarter of the 430 municipalities had chosen Uloba as their personal assistance provider. This corresponded with the figures reported during an interview with Jan Andersen in 2011 on personal assistance in Norway (Westberg, 2011). Upcoming legislative changes, such as the introduction of a Norwegian Standard 2014 set out regulations for the employment of personal assistants, and in 2012 had led to fourteen municipalities in Western Norway refusing to comply. Asle, Uloba guardian, explained that municipalities can view Uloba as being too expensive. Asle continued that for many years municipalities have tried to under-cut Uloba with cheaper local personal assistance agencies.

Asle believed that many other providers had lost the goals of independent living; peer support is often non-existent, disabled people are under-represented as employees and service users can lose control over choice of personal assistants. These issues were also highlighted in an interview with Jan Andersen in 2011 who discussed the challenges Uloba encountered within a competitive market for personal assistance provision (Westberg, 2011). Uloba founder Kris described several ways in which the Norwegian municipalities' personal assistance process disempowered disabled people:

> **Kris:** *"...if you have local assistance from the local government they want to decide. They hardly put the ad in the paper. They use someone they can use for other things as well and they give you two, three people to choose from and then they want to be in control… We just found out that nobody can work more than nine hours per day. And we used to have eleven before it was over-time. With overtime, you can't plan overtime... it makes a hell of a life for people who have a lot of assistance and also for the assistants."*

Uloba guardian Asle explained that often external personal assistance agencies were envious of Uloba's profits. However, what they failed to understand was that Uloba is a cooperative and everything goes towards the user led services and that the small percentage they take from co-owners supported a high quality of service provision for personal assistants, as well as co-owners. Similarly, Uloba regional leader Skule thought these agencies did not respect the twenty years of experience Uloba had gained in personal assistance service delivery. They viewed it as an area to make profits and many had even tried to convince co-owners to leave Uloba and join their agencies because they viewed personal assistance as a business.

Skule stated that Uloba operates Norway-wide, with the aim of benefiting disabled people across the entire country. This meant that disabled people received the same personal assistance service without geographical disparities. Uloba's in-built peer support also ensured that individuals were trained before embarking upon the new demands as employers of personal assistants. Skule concluded that *"they have kind of forgotten the meaning of Uloba and of independent living and of what we're doing."*

Roulstone and Hwang (2015) argued that the future for user led Centres for Inclusive Living rely upon a restructure of their role within national governance frameworks. Firstly, Centres for Inclusive Living create specialised collective solutions towards, for instance, the delivery of personal assistance services that respond to personal entitlement and collective use. Such an approach would need to be supported by core funding from the state and a recognition that Centres for Inclusive Living operate on a level basis with other key bodies.

### 6.2.3 Summary

To summarise, in line with Lowe's meso level governance analysis the meso level narratives of personal assistance shared by participants demonstrated the interaction of structural, national policies and organisational practices, and agency lived experiences of disablement. Both GCIL and Uloba research participants outlined that user training and personal assistant training was an important method of empowerment for disabled people (Shakespeare, 1998). At a macro policy level, the care professionals in Scotland and Norway lacked the inclusion of mandatory

educational courses to create a high quality personal assistance delivery. Instead, both organisations operated user led training to enhance the micro level, lived experience of personal assistance for disabled individuals.

Both case study organisations encountered a lack of appropriate resources to operate personal assistance services that ensured disabled people's control over the entire personal assistance process. Although disabled people have the right to be assessed for personal assistance in both Scotland and Norway, powers of decision-making were at a meso level (local authorities and municipalities) on whether support would be granted and how much (Roulstone and Prideaux, 2012; Westberg, 2011). Austerity measures in both countries followed a political rhetoric that expenditure on personal care must be reduced. A consequence of this political rhetoric involved the tightening of eligibility criteria set out by local authorities or municipalities; disabled people with less severe impairments or low level need were excluded from access to personal assistance at home.

Research participants argued that user led personal assistance would address issues around the quality of service delivery and effective use of resources. However, authors such as Roulstone and Hwang (2015) point out that Centres for Inclusive Living, which are key drivers for user led governance, needed to be supported by macro decision-making centres set up in each local authority area and recognised as a viable opportunity to explore alternative collective approaches towards the provision of personal assistance for disabled people.

## 6.3 Micro Narratives of Personal Assistance

The micro narratives of research participants highlighted three sub-themes. Personal Assistant Recruitment identified the challenges around the process of recruiting suitable personal assistants. The second sub-theme, Personal Assistant Attributes' explored the key elements of an effective working relationship. The final sub-theme, Disabled Employees and Personal Assistance also examined the support for research participants in employment. Research participants outlined the ways in which personal assistance in the workplace differed or mirrored the delivery of personal assistance within the home environment.

### 6.3.1 Personal Assistant Recruitment

The micro narrative from research participants corresponded with the findings from Christensen and Pilling's (2014) study into personal assistance in England and Norway. According to Christensen and Pilling (2014), the UK system provided users of personal assistance with greater choice and control from the outset of the recruitment process, while, at the same time, users experienced greater insecurity due to variable circumstances under the simultaneously stimulated care provider market. Contrastingly, the Norwegian situation allowed more opportunities for disabled people to exert control over the recruitment of personal assistants in a climate of a less diverse care provider market.

Research participants in both countries indicated challenges with the recruitment process for personal assistants. GCIL service user Jessie outlined that there were tensions around autonomy and flexibility. For instance, if an individual had complete control over the hours of their personal assistant's package, then they could adopt a flexible approach to accommodate spontaneous events but this may clash with the wishes of some personal assistants. Jessie noted especially that employing individuals through an agency required rigidity of hours. Although, when a personal assistant is off due to sickness the agency was responsible for providing personal assistance cover. Pip concurred that advertising for a stand-in is even more difficult because you're unable to offer a specific number of regular hours.

All GCIL service users employed multiple personal assistants. Some recounted situations where a certain employee did not work out. For example, Jessie had issues with one who was unable to operate the hoist properly. Instead of addressing any difficulties with Jessie directly, the personal assistant reported that Jessie was trying to use the hoist on their own. This discord soon led to that personal assistant leaving for alternative employment.

GCIL service user Alex remarked that they felt like they gained a reputation as a difficult client with their agency while ascertaining a trustworthy personal assistant. A couple of the personal assistants, Alex explained, *"turned up to the house looking like they needed care themselves"*. Alex rang the agency to voice their concerns

and demand alternative personal assistants. The impression given was that the agency was not used to service users delivering critical feedback.

A few of the Scottish participants discussed challenges encountered in attracting and retaining suitable people as personal assistants. As GCIL service users Alex and Jessie noted, there were concerns around the level of wages bestowed upon personal assistance. Alex remarked that often personal assistants received the minimum wage. This, Alex felt, belittled the work that they performed and tended to attract: "...*people who are not the sharpest tool in the box*." By this remark, Alex was referring to the fact that many personal assistants lacked appropriate training or investment in their continual professional development in order to ensure a high quality of care.  Jessie meantime commented that wages stayed fixed, without increases in line with inflation or in recognition of length of time in service. A lack of financial incentives can de-motivate individuals and Jessie remarked that most eventually left in search of better paid employment opportunities.

Guldvik (2003) noted that in Norwegian society, specific attributes are associated with personal assistants and the recruitment process. These included that the personal assistant works for one person, undertook duties inside and outside the home, the user was involved with the recruitment process and that the user managed the personal assistance work. Due to the boundaries set out between employer and employee, a few participants commented that Uloba advised against using friends and family as personal assistants. The boundary between friendship and a working relationship was discussed in many participants' narratives. Senior Uloba manager Bronnil remarked, for instance, that especially when an individual is new to using personal assistance, it is easier to make mistakes with somebody you do not know. Bronnil asserted that mistakes create difficulties for disabled people to mould their assistant into what they want and can potentially damage friendships along the way. They also noted that the media has picked-up upon rare situations where co-owners had married their personal assistants. Such occurrences ignited questions around power relations and decision-making capabilities of a perceived vulnerable group within Norwegian society.

Uloba regional leader Skule outlined the process of recruiting a personal assistant. After advertising on the side of buses and on the Norwegian job vacancy website, Skule described that the selection process was based on the gut feeling they had when interviewing job applicants. Of course, practical qualities played a role too, and co-owner Per highlighted that for them, time management, ability to cook, getting along with other family members and willingness to respond to instructions were also essential qualities for an effective personal assistant relationship.

### 6.3.2 Personal Assistant Attributes

The lived experiences of research participants indicated different types of personal assistance relationships between the user and assistant. Ungerson (2005) characterised the nature of care as either 'warm' or 'cold'. The former was a relationship that was intimate, familial and enduring, and the latter often occupational or professional, limited in time and focused primarily or exclusively on mental and physical wellbeing. Scottish participants tended to describe 'cold relationships', often due to a high turnover; whilst Norwegian participants tended to describe 'warmer relationships' due to the lower turnover of assistants and the building up of rapport.

In both countries, research participants corroborated Guldvik's (2003) finding that key qualities for personal assistance interactions include communication, respect and tolerance. For example, the importance of trust arose during a few participants' discussions about the role of their family with personal assistance services. GCIL front-line employee Sandy spoke openly about their anxieties as a parent when leaving their son in the charge of others for the first time. Their young son has cerebral palsy and was unable to walk or talk and had had seizures. Sandy asserted that:

> **Sandy:** *"Somebody could tell us he's had a great day, you know, and they could leave him in a corner and he just wouldn't be able to tell us that he's been left in a corner. I've got enough decent people that nobody would do that, just have enough faith that the people in the schools and the clubs that he goes to love him, he's got a very very happy, very very smiley kind of personality about him. But, I don't know."*

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GCIL service user Ali pointed out that an important element of a relationship with a personal assistant centred on trust. For example, there was one individual in particular from whom Ali felt comfortable receiving help with financial correspondence. Ali reported that an effective relationship was evident when a personal assistant automatically did little tasks without being asked, as well as on a more practical note, getting along well with the household cat and other family members.

GCIL service user Pip told of the challenges of switching from parental assistance to personal assistance. Pip loved the way that their mum used to help lift them onto the loo, help shower or make meals. It took a while until it felt comfortable for a stranger to carry out such intimate tasks and in the preferred manner. Pip also recounted that this process flourished when they moved into their own place since personal assistants coming into the family house was viewed as undesirable by Pip's parents. The other aspect of this journey was learning to accept the use of a hoist. Pip said some reluctance stemmed from fear of the unknown and that once it became apparent that the hoist was hidden up in the ceiling and that it saved physical effort on their part as well as the personal assistant, Pip wished they had used a hoist much sooner.

Turning to Norway, research participants' narratives mirrored those revealed in Scotland. The first theme discussed centred on what personal assistance users looked for in their assistants and whether they had encountered any negative experiences. Uloba co-owner Per explained that they encountered a personal assistant who placed greater value on their paid position rather than Per's wellbeing as a person. One day Per was getting picked up by ambulance in an emergency and the personal assistant asked if on the way to the hospital they could first drive her to the bus stop. Per commented that this was not a good sign that they would have a long-lasting working relationship. Other Norwegian participants pointed out that relationships between service user and personal assistants relied a lot on initial reactions to interactions and intuitive feelings.

Kristian, senior Uloba manager, for instance, reported that they knew immediately the moment they opened the door and liked the first impression, especially of the

character, of the applicant; while Skylar remarked that the moment it was apparent an applicant was suitable occurred once when a lady walked in, bonded with the cats and admitted to being a fellow Elvis fan. All participants highlighted that they tried to determine which tasks certain personal assistants would be best at performing. For example, former Uloba regional leader Aren described that:

> **Aren:** *"I tend to focus on the things that they're good at. One I use for office work, accounting stuff like that. I have one who's very handy and he helps with things like doing thing to the house, fixing my car. So I try to focus on what they're good at but they don't have any different qualifications or that."*

However, Aren continued that at the beginning they were not sure what to look for in potential assistants. It came down to good chemistry and luck. Of seven personal assistants who commenced employment with Aren in 2006, four remained in their employment. Aren tried to adopt a flexible approach whereby the boundary between friendship and employer can become blurred. As Aren explained:

> **Aren:** *"At the beginning I tried having a distance between myself and the assistance and try not to get too personally attached or get too friendly but I kind of figured out that, that's not my personality. Personality as in the way it would be try to have a relationship with one of my assistants. So we're friends but at the same time I find it's not that hard to see the boundaries or tell them that's there's something that I want to change. I used to do that sometimes, in private or with the whole group; I'd say I'm not happy with this and this and this. So far I've not had any conflicts in friends and, of course there's sometimes then it's harder to tell somebody, but so far it's going pretty well."*

It should be noted that this doctoral research did not gather the views or experiences of personal assistants in Scotland and Norway. It was not possible to uncover whether personal assistants preferred a certain style of employer. However, Guldvik's (2003) study suggested that some personal assistants report problematic aspects connected with their job, including conflicts surrounding a desire for stable tasks/fixed hours when users wished for flexibility, and a tendency for users to involve assistants too much in private affairs. Guldvik's (2003) survey

found that two out of five personal assistants speculated that they would be likely to leave their job, whereas an equal proportion stated they would certainly continue and one out of five planned to definitely quit their job.

### 6.3.3 Disabled Employees and Personal Assistance

Another area where research participants in both countries spoke about personal assistance was in relation to employment. Alex (GCIL service user), for instance, recalled their reluctance to enter paid employment, especially at a lower starting salary, as they believed that most of their wages would go towards travel to and from work. However, through GCIL's Professional Careers project the Access to Work scheme came to light. This is a UK national government funded program to financially assist disabled employees.

Access to Work covered Alex's taxi journeys to and from work each day and any personal assistance services required in order to carry out employment related tasks. Similarly, Pip used Access to Work for travel, a personal assistant and adaptations to the work environment. At one point, Pip recounted, a one-handed keyboard was purchased that aided their ability to type. It was quite a small change but made a significant positive difference. Aren (former Uloba regional leader) also remarked that Norway had a scheme called Professional Based Assistance, which arranged personal assistance service through Uloba but with a focus on support within employment. However, this can take a few months to set up.

In the Norwegian survey, an anonymous respondent highlighted the lack of coordination of aids/personal assistance support for disabled people in employment and pointed out that this hindered disabled people's access to independent living. They remarked that too many support agencies are ineffective and delays occurred in relation to the receipt of aids that are needed. They also remarked that the second goal of the Inclusive Working Life Agreement (IWLA) has not been reached. The IWLA was set out in 2001 by Norwegian social partners and the Norwegian government. It sought to implement a strategy between 2001-2005 to reduce sickness absence in the workplace, increase the employment rates of disabled people and to increase the age of retirement (Lismoen, 2003). However, by 2009, the second objective that focused on disabled people had not

been met and at the time of fieldwork in 2012, the IWLA had set out plans to concentrate upon increasing employment for disabled people less than thirty years of age, supporting the transition from education to the workplace (Norwegian Government, 2012).

Another issue picked up by a participant concerned the employment rule that when a person became ill and was granted their full disability pension, it was obligatory that they did not work for a year. However, this respondent pointed out that it would be more beneficial for the individual if they could choose to participate in as many hours of their employment as they felt able. Any over-payments of their disability pension could be returned via gradual instalments during the following years. Quite a few survey respondents had future personal goals around increasing knowledge and access to user-controlled personal assistance. For example, a representative from the Norwegian Association of the Disabled (Norges Handikapforbund) stated that:

> *"I want to move to a country outside the EU. I want to hire, train and to be the employer of my assistants. After I've established myself in this country, I want to spread awareness among that nation's 'disabled people' about their opportunities and ability to become more independent. I want to establish learning centres. Dependent on how much spare time and energy I might have, I will also try to influence the country's government to take a different view of their 'disabled people'."*

### *6.3.4 Summary*

In summary, the lived micro narratives of personal assistance highlighted the lived experiences of personal assistance in Scotland and Norway. The recruitment process of personal assistants in both countries reflected the welfare typology (Esping-Andersen, 1990) and corroborated the findings from a 2014 study into personal assistance in UK and Norway; Scottish participants faced challenges to attract and retain suitable assistants due to low wages and a lack of value placed upon the caring profession, whereas Norwegian participants reported greater satisfaction and longer retention of assistants due to incremental wages in line with other health professions and reward for loyalty.

According to Ungerson's (2005) typologies, the Scottish and Norwegian participants' narratives demonstrated opposing types of personal assistance relationships. The former exhibited cold types of relationships, with assistants showing detached, short-term interest in their position, whilst the former exhibited warmer types of relationships, with assistants showing commitment to their work and engagement with the user. The process of personal assistance for disabled employees also highlighted contrasts. In Scotland, a UK national agency called Access to Work controlled and delivered support in the workplace, compared to the user led model adopted in Norway that involved Uloba administering a separate employment assistance related account for a co-owner.

## 6.4 Significant Findings of Personal Assistance

Adoption of a social relational model of disability (Thomas, 1999) contributed towards the analysis of the area of personal assistance and helped with the analysis of the interplays between structural factors and lived experiences of disablement. Attention to the role of governance (Lowe, 2004) complemented this approach to highlight the macro, meso and micro level narratives from research participants. Firstly, the themes uncovered corroborated existing literature, as well as providing a unique snapshot of lived experiences of personal assistance in 2012. Secondly, research participants described the interconnections between personal assistance and peer support.

The existing literature on personal assistance in Scotland and Norway was corroborated by research participants' narratives. For example, GCIL and Uloba provided guidance and user led operationalisation of personal assistance services. However, both reported challenges surrounding the lack of appropriate levels of resources and that obstacles were encountered preventing full user-control. In Scotland, Rummery and Fine (2012) pointed out that the value system of care in the UK needed to be reconstructed. Low wage rates, a lack of career progression opportunities and stigmatisation of care givers all posed challenges for the Scotland research participants to recruit and retain suitable personal assistants.

In Norway, although personal assistants received pay equivalent to health and nursing professions, participants highlighted difficulties for user led personal assistance services. An interview with Jan Andersen highlighted that control over eligibility and amount of support for personal assistance in Norway lies with the Norwegian municipalities (Westberg, 2011). The municipalities also decided whether Uloba could act as the service provider. Research participants all shared experiences of challenging municipality decisions concerning their personal assistance and, in some cases, participants from Western Norway had Uloba withdrawn due to a refusal by specific Norwegian municipalities to adhere to working conditions for personal assistants.

One of the strengths of this doctoral research was the ability to provide a snapshot of disabled people's views and experiences. The fieldwork was carried out in 2012, before the Self-directed Support (Scotland) Act (2013) and the Norwegian Standard (2014). The data captured the views and lived experiences of personal assistance where many research participants voiced concerns and apprehensions for the future quality of personal assistance in both countries.

The macro, meso and micro level narratives from research participants highlighted interconnections within the area of peer support. Personal assistance forms one of the 12 Pillars of Independent Living (Spectrum, 2016). In Chapters 4 and 5, it was proposed that the peer support pillar acted as a foundation for the remaining eleven pillars, and the data surrounding personal assistance corroborated this proposal.

At a macro (national policy) level, participants discussed that although disabled people have the right to be assessed for personal assistance in both countries, powers of decision-making in relation to whether applicants are granted assistance and how much lies with meso level care providers (local authorities and municipalities). However, policy changes had occurred as a result of the collective pressure from disabled activists. For example, the Community Care (Direct Payments) Act (1996) was introduced in the UK through efforts from the Disabled People's Movement (Roulstone and Prideaux, 2012). Similarly, in Norway user controlled personal assistance was legalised in 2000, but Uloba campaigned to extend powers to people with cognitive impairments to engage a guarantor to help

shape their personal assistance. In 2005, this change was implemented into national policy.

At a meso (organisational) level, peer support was a key method to ensure a high quality of personal assistance. For instance, both GCIL and Uloba invested time in the training of users and personal assistants. For users, it was important that basic skills around being an employer could be learnt, while for personal assistants it was important that individuals understood the ethos of independent living. The ability of user led GCIL and Uloba to draw upon peer support placed them apart from other personal assistance providers, such as private agencies or local authorities/municipalities.

At a micro (agency) level, the lived experiences of research participants explored the connections with peer support. During the recruitment process of personal assistants, GCIL service users and Uloba co-owners relied upon word of mouth to find suitable assistants and negotiate the best type of working relationship. However, in Scotland, due to high turnover of personal assistants, cold personal relationships were cited, while in Norway a lower turnover may account for warmer personal assistant relationships (Ungerson, 2005).

## 6.5 Conclusion

This third findings chapter presented data that revealed the theme of personal assistance throughout research participants' narratives. Personal assistance also forms one of the 12 Pillars of Independent Living (Spectrum, 2016). A social relational analytical framework (Thomas, 1999) was adapted to the area of personal assistance and revealed structural factors as well as lived experiences. As outlined in Chapter 4, peer support provides a foundation to facilitate disabled people's access to personal assistance and, more broadly, access to independent living.

Across macro (national policy), meso (organisational) and micro (agency) level accounts of personal assistance, research participants demonstrated application of pliable and rigid forms of peer support; the former informal, intangible actions such as word of mouth that provided means of recruiting suitable personal

assistants and the latter formal, tangible governance structures such as user led training of users and personal assistants.

In addressing the overall research aims, the micro level narratives of personal assistance illuminated what Thomas (1999) referred to as structural challenges for disabled people's access to independent living.  Mainly, participants' access to personal assistance required autonomy over the recruitment and retention of assistants. As reported by research participants, there were divergent types of working relationships (Ungerson, 2005) which reflected the welfare approach (Esping-Andersen, 1990). Scottish participants had a liberal mixed market regime and encountered cold relationships due to a high turnover of personal assistants, whereas Norwegian participants had social democratic policy and were less subject to market forces, and therefore experienced warmer working relationships due to a lower staff turnover and time to develop trust.

This research did not include the views or lived experiences of disablement from disabled people with no contact with GCIL or Uloba. A comparison between the role of peer support within their perspectives and of those in the existing data set may have revealed to what extent peer support facilitated access to personal assistance. Additionally, the research did not include the views or experiences of personal assistants. Findings from Guldvik (2003) suggested that personal assistants regard issues such as the sharing of private information problematic, and this may have provided a useful comparison to the users' perspective.

The narratives of personal assistance at a meso (organisational) level uncovered governance structures that have been adopted by GCIL and Uloba and enhanced disabled people's access to independent living. The main ways that GCIL and Uloba utilised peer support to facilitate access to personal assistance was through training of users and personal assistants. Although the finance streams worked differently in both countries for personal assistance services, there was a convergence in the concerns GCIL and Uloba participants held about the lack of appropriate resources. On one hand, austerity measures in the UK have retracted eligibility criteria for potential recipients of personal assistance, and on the other hand, austerity measures have created a power imbalance, with municipalities

determining whether a disabled person receives services or if Uloba could be the provider and how much support is required.

At a macro (national, decision-making) level, research participants' narratives around personal assistance in Scotland and Norway demonstrated various challenges for disabled people's access to independent living. Across the 12 Pillars of Independent Living, neither country exhibited disabled people's autonomy over all decisions in relation to the delivery of personal assistance to personal assistance (Duffy et al., 2010; Westberg, 2011). Research participants explored the debate surrounding whether disabled people should be expected to contribute towards the costs of care services. Responses reflected the welfare typology where the individual lived. For instance, the Scottish respondents believed that personal assistance should be free, whilst the Norway response supported a means-tested approach in a social democratic model, with the emphasis upon a contribution through a work ethic (Bay and Pedersen, 2003). Both countries show scope to adopt what Bickenbach and Cooper (2003) termed a holistic policy approach towards independent living, including personal assistance, and to ensure that policy was informed by a rigorous and relevant evidence-base. For instance, they put forward that societies should examine disabled people's access to independent living in terms of participation indicators where citizen outcomes can be monitored.

The three findings chapters have presented data around peer support, accessible housing and personal assistance. All of these areas are among the 12 Pillars of Independent Living and the evidence suggests that peer support, in particular, provided the foundation for the remaining eleven. The following chapter presents an overall discussion of the findings.  It will also examine the overarching theoretical and practical applications, and indicate where future research is needed.

# Chapter 7. Future Facilitation for Independent Living

## 7.0 Introduction

This chapter presents an overall analysis and discussion of the findings in relation to the wider theoretical and research literature. As outlined in the three preceding chapters, research participants situated their discussions on disabled people's access to independent living within the areas of peer support, accessible housing and personal assistance. These three areas are also three of the 12 Pillars of Independent Living (Spectrum, 2016), as discussed in Chapter 2.

As set out in Chapter 3, the theoretical framework adopted by this study drew upon the social relational model of disability (Thomas, 1999) and meso level governance analysis (Lowe, 2004). This methodological approach required the collection and analysis of qualitative data that provided insights for the three research questions:

1. What practices or policies facilitate or impede disabled people's access to independent living?

2. In what ways do the governance structures of Centres for Inclusive Living enhance disabled people's access to independent living within societies?

3. Does the nature of self-identification affect disabled people's experiences of, and access to, independent living?

This chapter is divided into four sections. The first section, Theoretical Insights, outlines the merits of such an approach and reflects upon the type of information gathered from research participants in order to investigate the overall research questions.

The second section, Meso Facilitators and Connections to Independent Living, discusses the key mechanisms through which the case studies were shaped by policies and practices. From the research participants' identification of meso facilitators for disabled people's access to independent living, this section outlines

the interactions with other tiers of society. For example, meso level facilitators are dependent upon the ability to influence macro (structural, national policy), meso (organisational) and micro (agency) levels of decision making.

The remaining sections explore the cross-tier relationships with the meso level in more depth. The third section, Meso Connections and Macro Relations, highlights the theoretical contributions set out in the literature review in Chapter 2 on concepts of independent living, citizenship and governance. This section also examines the interactions between the meso level and macro national decision making in order to facilitate disabled people's access to independent living.

The final section, Meso Connections and the Disabled Self, discusses the meso level interactions with disabled and non-disabled people at a micro level that facilitate independent living. In particular, this study highlights the ways that meso connections deepen understandings around the role of the 'impaired' identity and lived experiences of disablement. The chapter closes with a summary of the main empirical contributions presented throughout Chapter 7 and outlines the objectives of Chapter 8.

## 7.1 Theoretical Insights

A key contribution to this research was the complementary use of the social relational model of disability (Thomas, 1999) and meso level governance analysis (Lowe, 2004). The literature review in Chapter 2 identified limited use of this approach prior to fieldwork in 2012. Instead, disability studies in the UK had emphasised the social model of disability (Oliver and Barnes, 2012) and in Norway a significant Foucauldian influence had stimulated post-modernist discourse analysis (Tøssebro, 2004).

The social relational model of disability was used to explore the macro structural (national policy making) barriers that may hinder disabled people's full participation within society. Simultaneously, it was used to explore micro agency level (lived experiences of disablement), psycho-social dimensions to interactions, power relations and the state of an individual's wellbeing (Thomas, 1999). For example, Thomas' framework was applied to a disabled person seeking employment who,

on the one hand, encountered structural level financial disincentives within the social security system to obtaining short-term employment and, on the other hand, experienced micro agency level attitudinal prejudice from prospective employers and others (Drake, 1999). Furthermore, disabled people seeking work exhibited low self-esteem without positive disabled role models. However, if disabled peers were present, power conflicts may still arise if they held different beliefs surrounding employment schemes for disabled people that followed integrated as opposed to separatist strategies.

As outlined in Chapter 3, this study adopted a meso governance analysis to complement the social relational analytical framework. Such an approach enhanced the social relational model because Thomas' (1999) work lacked recognition or discussion of the meso mechanisms involved with disabled people's sense of self or access to independent living. In addition, the existing empirical studies that have adopted the social relational model have not examined the role of meso level organisations, including disability related organisations, within disabled people's lives.

The inclusion of Lowe's (2004) governance analytical lens alongside the social relational model facilitated a meso level focus for this research. For example, it highlighted the specific governance structures that affected the power of the Centres for Inclusive Living included in this research to act as barriers or facilitators for disabled people's access to independent living. On this basis, it was possible to examine the interconnections with macro level (policy decision-making arena), meso level (relationships or partnerships with other disability related organisations) and micro level (users' individual action and forms of self-governance).

The integration of the social model of disability (Thomas, 1999) and Lowe's (2004) governance analysis enabled the collection of qualitative data that reflected societal cross-tier lived experiences of disablement in Scotland and Norway. The methodological approach required qualitative methods, including two organisational case studies, semi-structured interviews with disabled service users, semi-structured interviews with key experts and a predominantly open-

ended style online survey. The findings addressed the three research questions within this study.

The methodological focus on meso case studies within the Glasgow Centre for Inclusive Living (GCIL) in Scotland and Uloba in Norway also enabled a comparative approach across the two countries. Simonsen (2005) pointed out that cross-comparative approaches within disability studies can be useful to identify convergences or divergences between policies, practices and lived experiences of disablement in different countries. According to Esping-Andersen's (1990) welfare state typology, Scotland adheres to the characteristics of a liberal regime and Norway to a social democratic regime. Therefore, this study needed to pay close attention to research participants' narratives that highlighted shared historical developments, as well as different socio-political experiences and practices at national, regional or municipal levels and were influenced by various factors and actors.

**Table 7.1 Societal Multi-tier Facilitators**

| Level | Facilitators |
|-------|--------------|
| **Macro** | Rights to independent living; coordinated policies for independent living; independent ethos towards eligibility and funding; disability studies |
| **Meso** | Peer support; user-controlled services; coordinated services for independent living and disability studies |
| **Micro** | Disability studies; user-controlled resources; autonomy; access to information; self-governance |

Source: Author

As discussed in Chapters 4, 5 and 6, the research participants' narratives prioritised the areas of peer support, accessible housing and personal assistance. Table 7.1 illustrates these shared key facilitators across the three areas for disabled people's access to independent living at the micro, meso and macro levels within societies. The following section considers the meso level mechanisms as linchpin mechanisms through which policies and practices can be shaped to enhance disabled people's lives.

## 7.2 Meso Facilitators and Connections to Independent Living

This study focused upon two organisational case studies of GCIL and Uloba. This produced meso level analysis, as outlined above, that enabled an exploration of the research question, 'In what ways do the governance structures of Centres for Inclusive Living enhance disabled people's access to independent living within societies?'

Research participants' narratives revealed the ways that the governance structures interacted across the different tiers of society. For example, the case studies explored interactions between macro national policy-making, meso case study internal governance processes, meso level partnership working with other disability related organisations and relationships with users at a micro level. The data presented within the three findings chapters showed that key meso level facilitators connected disabled people's access to independent living in Scotland and Norway. These facilitators were empowerment, peer support and user-controlled services.

Empowerment was the first meso facilitator and the data showed that it takes many forms. In concurrence with Shakespeare (1998), the research participants' narratives around empowerment denoted the means by which attitudinal acceptance was actioned, either by an individual's identity as a disabled self or by acceptance from others. The case study organisations demonstrated that empowerment could happen in different ways in different areas. For example, participants reflected upon the opportunities their organisation had to pursue explicit political campaigns that sought to tackle the barriers disabled people faced when accessing independent living. GCIL and Uloba have responded in different ways under political pressures directly related to their receipt of funding; GCIL is an apolitical organisation and Uloba is a political body. The GCIL found that its campaigns associated with disabled people's rights could be constrained due to reliance upon funding from, for example, specific local authorities.

The dependency of some GCIL services upon local authority funding made it difficult for GCIL to publicly oppose local authority actions that may hinder disabled people's access to independent living. Contrastingly, Uloba participants reported that they felt free to politically challenge Norwegian municipalities or even the

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Norwegian state to bring about change to enhance disabled people's access to independent living.

According to Uloba interviewees, Uloba experienced financial independence since the organisation received funds directly from the state through the personal assistance model. However, it is worth noting that Uloba participants did not explore this relationship further in their narratives to highlight whether their expression of independence referred to security of funding. For instance, there may have been a theme of potential dependency that was not voiced. Uloba may encounter some forms of state conditionality that it operates in a certain way or chooses to overtly campaign on specific issues, and if it does not, this would potentially jeopardise state support through the funding stream for personal assistance. Research participants also shared challenges of service delivery based upon municipalities' decision to recognise or not recognise Uloba as a service provider.

Both case studies showed how empowerment could be achieved, thus supporting disabled people to access and participate fully in all areas of life through practical engagement with the independent living ethos (Hunt, 2001). Both GCIL and Uloba staff exhibited altruistic motivations for joining the case study organisations. Their choice of employment was not driven by materialistic objectives, since in both Scotland and Norway some participants noted that higher rates of pay would be attainable in the private sector job market. For example, some staff members had chosen to leave corporate business-driven occupations that were financially rewarding to work in lower paid positions within the voluntary sector. Furthermore, within the Scottish context, there was the added insecurity about long-term funding for Centres for Inclusive Living.

The second meso facilitator identified from the findings was peer support. This underpinned every research participant's reflections on barriers and facilitators to disabled people's access to independent living in Scotland and Norway. GCIL and Uloba perceived peer support as facilitating attitudinal acceptance that disabled people are valued citizens. This was transferred to a macro level, laterally to other

disability related organisations or professions and to individual disabled service users or co-owners and their support networks.

As outlined in Chapter 4, research participants' narratives uncovered two types of peer support, namely formal and informal. Formal peer support was characterised by operationalised structures of peer support through user-controlled services, collective activism, peer support training groups or internal procedures. Informal peer support was characterised by flexible interactions between friends, family or acquaintances.

According to research participants, the empowerment of disabled people and peer support are actioned through the third meso facilitator, user-controlled services. This may be conducted through organisations across all sectors of society, as long as they adopted what Hirst (1994) referred to as deliberative democracy: governance structures that represent and reflect the views of all stakeholders. Rummery and Fine (2012) pointed out that user led services are able to maximise effective distribution of scarce resources to those in priority need. Therefore, users in partnership with front line practitioners have greater awareness of efficient measures for service delivery and strategic planning.

The data from this study supports Wansley's (2000) assertion that user led voluntary organisations are best placed to assess and distribute resources or service delivery. In both case study organisations, front-line staff demonstrated knowledge of the levels of need, the amount of resources required and the specific expertise to carry out prioritisation of scarce resources. For instance, many disabled people were approaching GCIL with anecdotal evidence of physical barriers they had encountered relating to inaccessible housing. GCIL does not provide housing directly, but Chris, the GCIL senior manager, outlined the working relationships at meso and macro levels. At a meso level, users were signposted to other housing related organisations that may be able to assist in the application for the provision of accessible housing. At a macro level, Chris explained that funding had been granted by the Scottish Government in 2011 to introduce a national accessible housing register, now known as Home2Fit, to assist disabled house seekers find suitable properties.

GCIL and Uloba exhibited contrasting approaches towards lateral relations with other disability related organisations. GCIL demonstrated active engagement with other organisations or service providers at a meso level to promote a user led governance model. For instance, GCIL had developed, nurtured and/or supported many different organisations that focused upon various aspects of independent living. It focused upon a commitment to the social model of disability. This strategy sought to address many of the attitudinal barriers that Scottish research participants in this study had reported within existing disability related organisations or by employers who adopted a medical model of disability. As explained by Drake (1999), the medical model of disability locates problems or barriers within an individual's impairment.

Uloba valued an independent stance at a meso level. According to many research participants, Norway had a lot of impairment specific disability related organisations that adhered to the medical model of disability. Participants in this study suggested that in some cases such organisations would dissuade disabled individuals from applying for personal assistance because it was deemed enforcement of dependency of an individual upon others. Uloba held a clear boundary line around non-interference into medical care matters. This frustrated co-owners and created tensions because they desired Uloba to either increase influence over existing service provision or to expand its remit into additional areas of social care.

Uloba increased its presence as a personal assistance provider and this had been recognised by Norwegian municipalities at a meso level. At the time of the fieldwork in 2012, Uloba was contracted by a quarter of Norway's municipalities (Andersen, 2010). However, the majority of research participants believed that attitudinal prejudice hindered progression for Uloba's user led governance model. For example, many municipalities had tried to undercut the service provision or question Uloba's approach. In addition, fourteen municipalities in Western Norway had excluded service provision by Uloba because the municipalities refused to recognise the rights of personal assistants.

Uloba actively campaigns at a meso and macro level for measures that will both reinforce and strengthen personal assistants' employment rights. For Uloba,

personal assistants' employment rights are a crucial component of the value system that underpins the delivery of a high quality personal assistance service. The organisation supports measures that create secure working conditions and contracts for personal assistants. For example, participants supported Uloba's decision to withdraw their services from fourteen municipalities in Western Norway due to their lack of fair employment conditions in personal assistants' contracts.

Interconnections with macro policy and value systems played an important part in supporting meso facilitators. In Scotland, a strong theme that emerged was that personal assistants generally received low wages and had no financial incentives to remain long-term or gain experience. This was designated by macro value systems. According to GCIL service users, this made it challenging to attract and retain individuals with the correct outlook and skill set. Contrastingly, Norway viewed personal assistance as being on par with other allied health professions, such as nursing. The views of the research participants in this study demonstrated these higher levels of satisfaction along with greater longevity of personal assistant working relationships.

### 7.2.1 Summary

To summarise this section, research participants' narratives highlighted that, as meso level organisations, GCIL and Uloba played an important role in providing connections for disabled people to access or maintain independent living. The facilitators that underpinned this role were identified as empowerment, peer support and user-controlled services. GCIL and Uloba demonstrated different forms or approaches towards the operationalisation or application of these three facilitators.

The following section will outline the ways that the case study organisations created connectors for disabled people's access to independent living at a macro level within society.

## 7.3 Meso Connections and Macro Relations

Research participants' narratives highlighted the ways that the case study organisations used empowerment, peer support and user led governance to build

connections so that disabled people could access independent living at a macro level. This information provided insight into the research question, 'What practices or policies facilitate or impede disabled people's access to independent living?'

As the literature review in Chapter 2 revealed, at the time of fieldwork in 2012, there was a lack of empirical research that examined the interconnections between citizenship, independent living and governance. For example, Esping-Andersen's (1990) welfare typology was influential in the general area of comparative research and highlighted the macro governance structures. However, his work failed to recognise the significance of independent living and the ways that independent living is operationalised by different societal value systems. As authors such as Morris (2001) and Beckett (2006) went onto highlight, disabled people's access to independent living is a prerequisite for their full citizenship.

The data from this study showed that the citizenship parameters set by Scotland's liberal and Norway's social democratic welfare regimes shaped the extent to which national governance frameworks adhered to what Lister (2007) outlined as central societal values of solidarity, justice, self-determination and recognition. The national outlook on Scotland and Norway's citizenship entitlements and rights in turn determined to what extent each of the 12 Pillars of Independent Living would be supported. For example, participants' narratives supported Esping-Andersen's (1990) conceptualisation of key characteristics of specific welfare regimes, whereby the value of solidarity featured significantly in Norwegian lived experiences of disablement, as opposed to those in Scotland. The essence of solidarity is that all citizens should receive societal provision to establish a financial foundation from which to gain stability towards potentially contributing towards communities in the future (Anderson, 2000).

Norwegian interviewees reported that access to an adequate income, one of the 12 Pillars of Independent Living, was actioned by a national social security system with generous disability related payments and ease of use for periods of employment or unemployment. Contrastingly, Scotland interviewees reported concerns surrounding level of income, especially in relation to social security and the potential restrictive outcomes upon their access to independent living. Figure

7.1 illustrates the relationships between Norway and Scotland's welfare regimes, value systems of citizenship and the 12 Pillars of Independent Living.
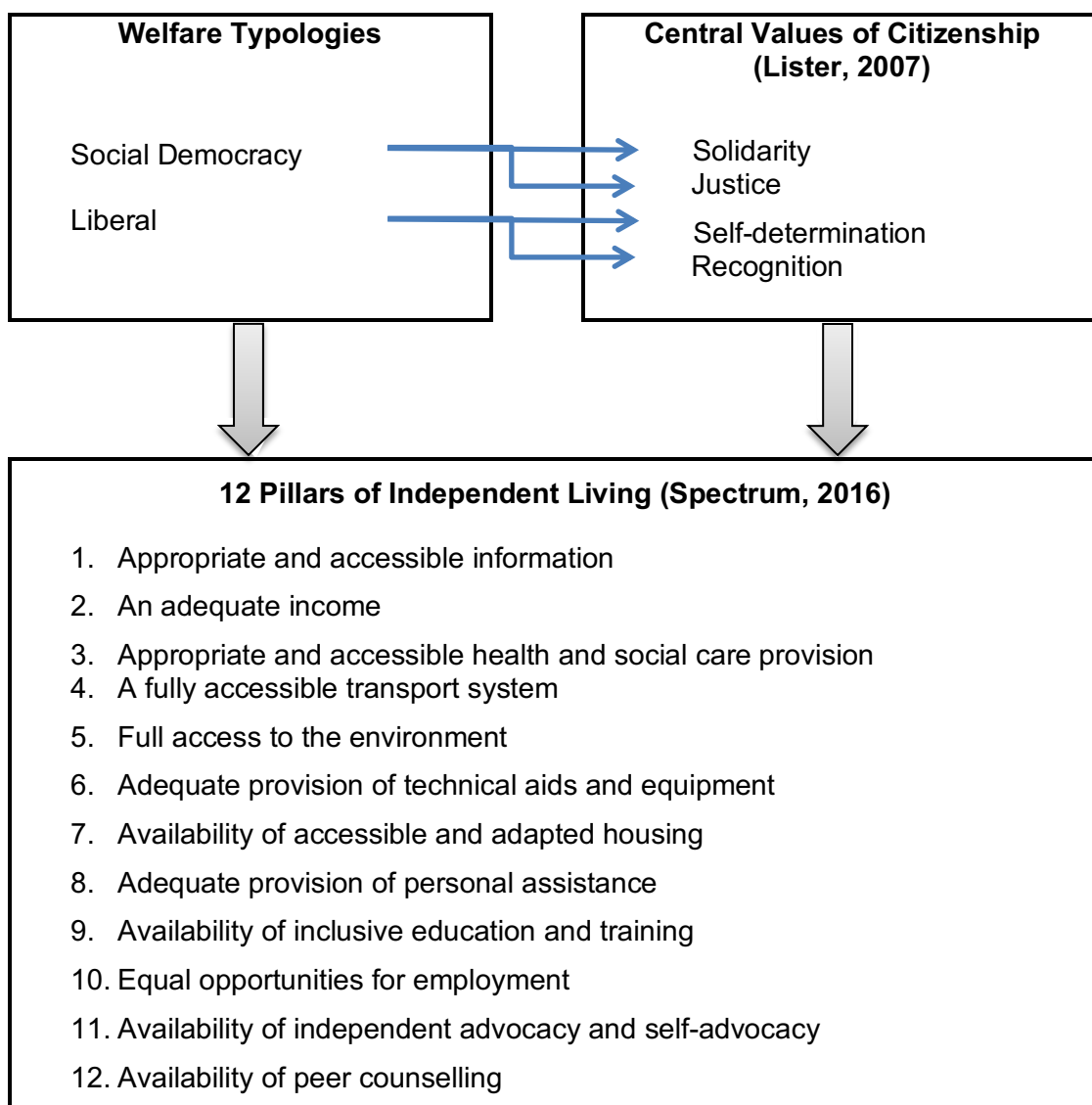
At the level of lived experiences of disablement in both countries, the different national approaches to specific pillars of independent living was evident from the variation in elements present for different areas of life for disabled people; for instance, in both countries the research participants highlighted peer support, accessible housing and personal assistance. In the area of peer support, participants' experiences reflected that disability studies is established in peer networks and education systems within Scotland and Norway, and that disabled people have rights to engage with disability research and theory. The remaining elements under peer support received some support in practice in both countries, especially through the work of GCIL and Uloba, but were not enshrined in policy or formally supported at a national level.

In the area of accessible housing, participants' narratives uncovered stronger support for specific elements in Norway, compared to Scotland. For example, universal design and accessible external environments are mandatory across the public sector in Norway (Discrimination and Accessibility Act, 2009) and this was evident from Norwegian interviewees' expectations for greater access of living spaces in the future. Similarly, although housing options were not subject to legislation in Norway, participants also indicated the existence of stronger practices through the role of the Husbanken. Both countries exhibited minimal support mechanisms for service user led planning and person-centred services, mainly through particular organisational practices.

In the area of personal assistance, Scotland and Norway have not granted a mandatory rights-based approach towards the assessment of disabled people's needs. All participants agreed that a rights-based approach would be an enhancer for their access to independent living in the area of personal assistance. Interviewees in both countries also reported that the lack of user autonomy impeded a person-centred approach towards personal assistance and that ad hoc practices that try to facilitate a person-centred approach were in place. In general, Norwegian participants' narratives demonstrated that Norway has stronger support

for the elements of attractive working conditions, appropriate wages and the training of personal assistants. This captured, for instance, that Uloba campaigns for the rights of personal assistants and a centralised approach towards training, and that it carries out training of all personal assistants employed by co-owners, ensuring a consistency of training delivery services.

**Figure 7.1 Interconnections between Citizenship and Independent Living**



| Welfare Typologies | Central Values of Citizenship (Lister, 2007) |
|---|---|
| Social Democracy | Solidarity / Justice |
| Liberal | Self-determination / Recognition |

**12 Pillars of Independent Living (Spectrum, 2016)**

1. Appropriate and accessible information
2. An adequate income
3. Appropriate and accessible health and social care provision
4. A fully accessible transport system
5. Full access to the environment
6. Adequate provision of technical aids and equipment
7. Availability of accessible and adapted housing
8. Adequate provision of personal assistance
9. Availability of inclusive education and training
10. Equal opportunities for employment
11. Availability of independent advocacy and self-advocacy
12. Availability of peer counselling

Source: Author

As Table 7.2 shows, there were different elements in practice that facilitated independent living within each of these specific situations.

**Table 7.2 Enhancers for Lived Experiences of Disablement in Scotland and Norway**

| Area | Key Issues |
|---|---|
| **Peer Support** | Disability studies; independent living ethos; Centres for Independent Living; shared frame of reference; empowerment. |
| **Accessible Housing** | Universal design; service user led planning; accessible external environments; person-centred services; housing options. |
| **Personal Assistance** | Attractive conditions; personal assistance training; rights-based needs assessment; person-centred services; attractive wages. |

Source: Author

Morris (2001) sought to enhance disabled people's access to citizenship by pointing out the barriers around participation and supporting the ethic of care, whereby impairment should be viewed as a potential life event that can affect anybody at any time. Roulstone and Hwang's (2015) comparative study of Sweden and the UK also found that, at a meso level, Centres for Inclusive Living provided significant practical support for disabled people in order to address existing barriers to participation in independent living. In addition, Centres for Inclusive Living were well placed to identify and respond to the needs of disabled people across the 12 Pillars of Independent Living (Spectrum, 2016). This echoes Wansley's (2000) argument that voluntary entities, such as GCIL and Uloba, create an effective buffer between the state and individual users to work with available funding to meet priority needs.

In line with the social relational model of disability (Thomas, 1999), the data analysis highlighted the interplay between meso facilitators and macro level structural socio-economic barriers (Oliver, 1990) that hindered disabled people's access to independent living. Research participants' narratives explored the ways that national policies should recognise the continuum of the life course that reflected Morris' (2001) assertions surrounding the ethics of care approach. This draws attention to the need for policy making to apply a theory of impairment alongside a social theory of disability (Abberley, 1987; Goodley, 2010) by emphasising a continual two-way interaction between agency and structure (Thomas, 1999).

Although this study's findings focused upon three specific areas of independent living, research participants did touch upon all of the 12 Pillars of Independent Living (Spectrum, 2016). It emerged that, through variable interpretations of policies or the lack of regulatory enforcement, at the time of the fieldwork in 2012 disabled people were unable to access or assert full rights to each element of independent living. For example, research participants reported barriers within macro level accessible housing policies in Scotland and Norway. These barriers included a lack of mandatory regulation across all housing sectors and tenures, a lack of enforcement of existing legislative measures and a locomotion-centric (wheelchair-user) impairment approach towards accessible design.

In concurrence with Lid (2014), research participants in both countries held a consensus view that, at a macro policy making level, measures to enhance disabled people's rights to independent living must be enforced by the state. State enforcement of disabled people's rights would tackle the historical perpetuation of prejudice towards disabled people (Oliver and Barnes, 1998) through an uncoupling of specialist services or practices from the specificity of disabled people (Pullin, 2009). For instance, research participants in Norway reflected upon the macro implementation of a mandatory universal design principle (Weisman, 1992) under the Anti-Discrimination and Accessibility Act of 2009. Continual flexibility is a key element of universal design (Lid, 2014) in order to ensure a combined structural and agency approach whereby services or practices encompass universalistic accessibility and yet respond to person-centred needs (Thomas, 1999).

This study also found that disabled people's access to independent living needed to be supported by macro resources across all 12 Pillars of Independent Living (Spectrum, 2016). In both countries, specific areas received greater political recognition and funding. This may explain Uloba's approach at a meso level to pursue a personal assistance service model without direct input into other areas of independent living such as accessible housing. Its financial model was viewed as stable, secure and linear in nature since funds are provided by the Norwegian state and distributed to municipal service-providers.

Research participants from both countries outlined challenges to the inclusion of disabled people's views and experiences at macro policy making levels. One of these challenges involved gate keeping practices, particularly by care professionals.  As pointed out by Duffy (2007), gate keeping often hindered disabled people's access to independent living through a lack of recognition of disabled individual's autonomy over their circumstances. Consequently, there is a need for co-production at the national policy-making levels to ensure that the views and lived experiences of disabled people are incorporated into the policy making process. This would empower disabled people to control decisions that affect their lives, improve a coordinated policy approach towards the different areas of independent living (Swain et al., 2003) and ensure that the needs of all disabled groups are taken into consideration. Shakespeare (1998b) noted that the diversity of needs created tensions within the Disabled People's Movement. For instance, as French (1994) pointed out, some accessibility features, such as raised kerbs, can assist navigation for visually impaired individuals but can be a hindrance for wheelchair-users.

The Disabled People's Movement highlighted that the attention paid to disabled people's views can be tokenistic at a macro level (Campbell and Oliver, 1996). Therefore, empowerment (Shakespeare, 1998) is crucial to ensure that disabled people have autonomy and control over the decision outcomes as well as the decision-making process. Empowerment of disabled people within the macro decision making process and outcomes requires a co-production approach. Co-production denotes the highest level of user involvement (Sherman and Sherman, 2013). However, such an approach requires monitoring to ensure the representativeness of diverse stakeholders. In relation to disabled people, co-production should involve perspectives from locomotional, sensory and cognitive impairment groups.

In both countries, research participants highlighted potential areas of conflict between different groups of disabled people during macro decision-making. For example, the account by Audny, a Norwegian research participant, reflected meso and macro tensions around Scotland and Norway's shared policy approach since the 1990s for de-institutionalisation and community care (Means et al., 2003;

Tøssebro et al., 1996). Audny explained that their brother, who had a cognitive impairment, preferred to stay in an institutional setting with familiar social relationships and activities. However, this perspective conflicted with some other Uloba members because the Independent Living Movement advocated integration over separatist service provision (Hunt, 2001).

The account by Audny also highlights the interplay between empowerment and co-production. For instance, recent political rhetoric in Scotland has shifted from empowerment (that was prominent during the late 1990s due to the Direct Payments (1996) Act) to co-production (in relation to disabled people's access to independent living). As outlined in chapter 3, The Literature Review, Recent examples of co-production in Scottish policy are the Dementia Strategy 2013-2016 (Scottish Government, 2013) and the implementation of Scotland's National Action Plan for Human Rights 2013 - 2017 (Scottish Human Rights Commission, 2013).

However, co-production must reflect that one approach may not suit the needs of the many and this is where empowerment holds an essential role. In connection with social care in Scotland, a co-production approach was embraced by the Public Bodies (Joint Working) (Scotland) Act 2014. This act seeks to integrate adult health and social care services to enhance deliver, as well as provide statutory requirements for strategic planning. During strategic and commissioning processes, there is a legal requirement to include users of services. Users of services covers carers, patients/clients, organisations which provide services and professionals. Since the field work for this research was carried out in 2012, the participants' narratives do not provide insights in to the extent to which the co-production approach towards the provision of social care in Scotland, through greater user involvement, has resulted in a coordinated health and social care system that delivers appropriate services and support to those In need, at a time when most required.

The empowerment of disabled people through a co-production process must be supported by co-production outcomes. As noted in chapter 2, the literature review, since the co-production ethos and approach is relatively recent in gaining macro (national) level endorsement, guidance and advice are required in regards to the

implementation of co-production. The Co-production Network in Scotland website, for instance, contains resources, networking opportunities and case studies on the co-production approach (Scottish Co-production Network, 2016); while ILIS online toolkit for co-production outlines practical access considerations for the full participation of disabled people. Ollerton and Horsfall (2013) and Matthews et al. (2015) also point out that there is a need to ensure that a rigorous evaluation process underpins any co-production research strategy. Such measures will help to enhance disabled people's ability to shape effective dissemination approaches and encourage greater accessibility to project outcomes, including different forms of media. Co-production, as illustrated by Imrie (1999), must go beyond engagement and examine issues around methods of involvement, effective joint working and long-term sustainability of any co-production group.

The effectiveness of a co-production approach may be affected by factors posed by the Scottish model of policy-making discussed by Cairney (2016). According to Sir Peter Housden (2013), Scottish Minister and former permanent secretary, Scotland rejects the command-and-control style of governance exhibited by Westminster in England. Instead, the Scottish model draws upon new public management principles that centralise the role of evidence to inform democratic-accountable policy-making (Paun et al, (2016). Yet Cairney (2017) points out that the ways that evidence is gathered can influence the models of public service delivery.

Cairney (2016) outlines that there are 3 models of evidence-gathering adopted for policy-making: Models include: policy transfer built on a hierarchy of evidence and uniform delivery; story-telling approach which rejects evidential hierarchies and gives far higher autonomy to local actors; and, 'improvement science' collaborative model whereby a pluralistic approach is used for gathering evidence, combined with the ability of trained practitioners to experiment on the ground. Within these different approaches towards evidence-gathering, a strong emphasis is placed upon co-producing targets and outcomes with users, public bodies and local communities (see the Community Empowerment Act 2015). Co-production will be effected by some of the practical challenges surrounding this mixed-model style of policy-making. Cairney (2016) highlights for example that geographical location in

terms of Edinburgh-based organisations plus a significant availability of staff resources might provide advantages in attending Scottish government cross-party debates and networking opportunities. The organisational case study of GCIL in this research revealed constraints on staff resources to respond to online consultations by the Scottish government and an ability to get involved to a greater extent with a co-production approach towards policy-making in general.

### 7.3.1 Summary

To summarise this section, this research contributed empirical data that examined the policies and practices that enhanced disabled people's access to independent living. Considering these policies and practices led to an exploration of the interconnections between disabled people's citizenship, notions of independent living, governance opportunities and the specific facilitators highlighted by research participants' lived experiences of disablement. The case study organisations illustrated the ways that meso connections are or could be formed by macro policy making processes. For instance, the need for co-production decision making processes and outcomes, as well as political recognition of all of the 12 Pillars of Independent Living was necessary in order to empower disabled people, utilise peer support among disabled collectives and engage with a user led governance model.

The following section will discuss how the meso-level facilitators connect to the disabled self at a micro level.

## 7.4 Meso Connections and the Disabled Self

The meso level analysis (Lowe, 2004) in this study uncovered relationships between empowerment, peer support and user led governance with micro level factors. These micro level factors centred on participants' interconnections between the roles of impairment effects, sense of the disabled self and the ethic of care. This data provided an insight into the third research question, 'Does the nature of self-identification affect disabled people's experiences of and access to independent living?'

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Many participants mentioned agency level impairment effects, as outlined by the social relational model of disability (Thomas, 1999), during their narratives and the way that the recognition of a theory of impairment (Abberley, 1987; Goodly, 2011) could enhance an understanding of disability. Participants reported that their sense of identity involved internal dialogues about whether they accepted a disabled self. For instance, participants who self-identified as disabled explained that this identity held a temporal quality that often occurred in response to low self-esteem or discriminatory societal attitudes, practices or environmental obstructions. In this way, the narratives supported Thomas' (1999) explanation that situations, such as fluctuating health conditions, entail continual agency level assessment of the disabled self.

In concurrence, Shakespeare (1998) commented that pressure had grown to recognise the role of impairment within theory and practice. For example, a small degree of sight loss may have no impact upon a person's participation in society, especially if they have glasses tailored for their needs. Therefore, as Shakespeare explained, a dichotomy of impaired/non-impaired within populations is arbitrary because the severity of impairments or conditions can vary.

Additionally, Shakespeare (1998) noted that a sense of the disabled self is intertwined with the concept of empowerment. Empowerment, Shakespeare stated (1998), revolves around the decision-making power relation of everyday interactions. With this in mind, some GCIL service users and Uloba co-owners remarked on their limited control over the performance of particular tasks. For example, Ali and Per noted that housework could reflect a personal assistant's expectations of cleanliness rather than those of the user, and detract from the user's sense of home.

Peer support featured during participants' accounts concerning the acquisition of their impairments. Collective awareness and a sense of shared identity with other disabled people played an important role in enabling individuals to develop a sense of self-awareness and self-worth, and an ability to affirm a disabled identity (Corker, 1999; Keith, 1996). For most of the research participants, this journey began in

institutional settings, particularly amongst the founding members of the case study organisations.

Moreover, the notion of an ethic of care featured in participants' narratives on peer support. As discussed in the literature review, authors such as Morris (2001), Shakespeare (2004) and Hamington (2004) assert that societal value systems in relation to social care require recognition that caring entails empathy and emotional investment by all parties. As Shakespeare (2004) remarked, the performance of intimate personal care needs cannot be regarded with an emotionally detached, mechanical mind set since people and their bodies are not objects. The interactions of personal care, Shakespeare continued, involve emotional investment by the service user and the personal assistant.

The concept of empowerment is essential within an ethic of care. As Duffy et al. (2007) noted, social care delivery has been dominated by professionals without the inclusion of user needs. Ever since the emergence of the Disabled People's Movement, personal autonomy over personal assistance has been the main driver (Hunt, 2001). This study explored the area of personal assistance, where participants illustrated the ways that empowerment was enabled through informal and formal peer support, as defined by this research (see Chapter 4). Informal peer support was particularly useful during the recruitment process of personal assistants, whilst formal peer support helped with developmental or maintenance related aspects of personal assistance.

Informal peer support was significantly present during the recruitment process of personal assistants. Word of mouth was the most common method expressed by both GCIL service users and Uloba co-owners for finding suitable candidates. These were often acquaintances of friends or family, although many service users advertised via the case study organisations, particularly where several personal assistants were required.

National policy frameworks of Scotland and Norway had different impacts at the micro level of personal assistance. These policies contained different degrees of empowerment for disabled people. For example, Scottish participants reported the development of good relationships with their personal assistants, despite

challenging conditions under a liberal mixed market approach to social care. However, personal assistants tended to portray what Ungerson (2005) termed, a cold relationship. GCIL user Jessie, for instance, reported experiencing a high turnover of carers who had short-term ambitions to stay in that area of employment before moving on to a more financially rewarding prospect. In Scotland, participants discussed that due to the limited choice of people attracted to the profession and external agencies often acting as suppliers, it meant that personal assistants were often employed out of necessity, and sometimes not through the user's personal preference.

In Norway, users demonstrated greater choice over the nature of their relationship with their personal assistants. Many outlined what Ungerson (2005) called warm working relationships. For example, during discussions with Norwegian participants around the recruitment process, it was highlighted that the initial gut reaction when meeting a personal assistant for the first time was very important, as it guided the overall decision on whether to employ that individual. The value system in Norway, in which personal assistants are compared with the nursing profession, provided financial incentives for people to actively pursue a career in social care. This, participants highlighted, gave users a wider choice of personal assistants.

Morris (2005) noted that disabled people's access to citizenship and full participation in society entails attitudinal change through education. This theme was discussed by participants in this study, especially in relation to the need for good quality training for personal assistants. As Oliver (1990) recounted, society viewed disabled people as passive objects of care and similar concerns still pervades disability research (Duffy, 2010). Therefore, both case study organisations highlighted the need to instil the ethos of independent living to new potential personal assistants. GCIL manager Sam reported that training courses were being developed that would be delivered through local colleges to address the key aspects of the personal assistant role, including the need to adopt a social model perspective. However, the onus of responsibility was still placed on the user to ensure that personal assistants were informed about, and enacted, the principles of independent living.

Micro level narratives highlighted the interconnections with the meso facilitators of user led governance. Both case studies explored the strategies deployed by the organisations to increase the provision of information for potential new users. This was relevant, for example, to inform disabled individuals how to be an effective employer of personal assistants. A few of the participants highlighted that taking on user-controlled personal assistance entailed responsibilities, such as organising paperwork, making sure personal assistants received their wages, putting contingency plans in place for sickness amongst employees and recruitment of suitable candidates.

Case study staff in both countries recognised that user control could be a daunting experience for some individuals. Some GCIL service users and Uloba co-owners discussed their person-centred journeys towards employing personal assistants. GCIL service user Alex decided to relinquish control of certain elements, such as recruitment and emergency cover, to a private personal assistance agency. Alex indicated that having a degree of control within a person-centred approach was crucial so that service users could be empowered through personal assistance.

### 7.4.1 Summary

To summarise this section, the micro level narratives from participants highlighted interconnections with the meso level facilitators. The facilitators of empowerment, peer support and user led governance were present in different forms within participants' lived experiences of disablement in Scotland and Norway. For instance, these areas of personal assistance illustrated the ways that empowerment was connected with macro value systems around care, peer support (both formal and informal as defined by this study) and played important roles throughout the personal assistant recruitment and training processes. In addition, user led governance involved a person-centred approach towards the needs of disabled users so that empowerment was achieved through a self-determined amount of control.

## 7.5 Conclusion

To conclude, this chapter has further interpreted the data and findings in relation to the theoretical frameworks used and the wider body of research evidence. From the analysis of the participant interviews and the online survey, the core themes of peer support, accessible housing and personal assistance emerged. These themes were discussed in detail earlier in this thesis. The evidence base in response to the three overall research questions was gathered through a theoretical approach that adopted the social relational model of disability (Thomas, 1999) alongside meso governance analysis (Lowe, 2004).

From this theoretical perspective, the study identified facilitators of independent living at multiple tiers within society. This enabled an examination of the interconnections between macro strategic decision making, the meso level facilitators and micro level lived experiences of disablement. Three key meso facilitators that enhanced disabled people's access to independent living were uncovered by the research participants' narratives, namely empowerment, peer support and user led governance. This study contributed empirical research towards the understanding of interconnections between citizenship, independent living and lived experiences of disablement. At the time of fieldwork in 2012, the literature had not previously examined this combination of themes. A comparative approach ensured that the analysis was not dominated exclusively by the lived experiences of the researcher in one country. This enabled the researcher to be receptive to conditions or situations that may have challenged preconceived assumptions or values.

Research participants highlighted that disabled people in Scotland and Norway lacked or were unable to assert rights to all of the 12 Pillars of Independent Living at a macro level (Spectrum, 2016). Both case studies illustrated the ways that empowerment, peer support and user led governance acted as connectors to form relationships or services to enhance independent living. Research participants shared socio-economic structural barriers and agency level barriers (Thomas, 1999), as well as a consensus that meso facilitators were required to combat meso

level barriers, namely from disability related organisations that ascribe to the medical model of disability (Drake, 1999).

This thesis has strengthened the evidence-base that supports the significance of meso facilitation carried out by Centres for Inclusive Living in relation to the enhancement of disabled people's access to independent living. Roulstone and Hwang's (2015) study also found that Centres for Inclusive Living are essential user led entities that operationalise the inclusion of disabled people in society. For instance, user led governance results in the provision of inclusive policies and practices. These findings were corroborated by this research. GCIL and Uloba both emerged as key user led organisations that facilitated disabled people's access to independent living in Scotland and Norway, with the majority of participant narratives drawing attention to the cross-tier interconnections fostered by the case study organisations.

It should be noted that this study excluded disabled people who were not connected to the case study organisations. Therefore, further research would be beneficial to compare whether differences exist in the facilitators to independent living based upon disabled people's connections with empowerment, peer support and user led governance. Chapter 8 will provide an overview of the key learning points from this study and identify areas for future social enquiry.

# Chapter 8. Conclusions

## 8.0 Introduction

Chapter 8 highlights the key contributions made by this study. The chapter is divided in to three sections. The first section, The Implications for Disability Studies, presents the theoretical and methodological insights that this study provides towards the understanding and analysis of disablement.

The second section, The Implications for Centres for Inclusive Living, focuses upon meso (organisational) level contributions from this research. For example, the findings identified key meso level facilitators which enhance disabled people's access to independent living in Scotland and Norway. The section considers the potential implications for services run by Centres for Inclusive Living, in order to action this knowledge to create policy and practice changes.

The final section, Future Research and Practice presents suggestions to enhance the governance structures that facilitate disabled people's access to independent living across societies. This section also highlights potential avenues for further debate and social enquiry.

## 8.1 The Implications for Disability Studies

This study was unique in its examination of three research questions:

1.  What practices or policies facilitate or impede disabled people's access to independent living?

2.  In what ways do the governance structures of Centres for Inclusive Living enhance disabled people's access to independent living within societies?

3.  Does the nature of self-identification affect disabled people's experiences of, and access to, independent living?

This study's findings contribute towards disability studies in two ways. Firstly, the theoretical insights derived from the data address existing gaps in knowledge around the interconnections between disabled people's citizenship, independent living and governance. Secondly, the methodological approach integrated the social relational model of disability (Thomas, 1999) alongside meso governance analysis (Lowe, 2004).

As outlined in the literature review (Chapter 2), at the time of fieldwork in 2012 there was no research that combined conceptualisations of citizenship, independent living and governance towards the analysis of disablement. However, empirical research and theoretical explanations were evident in different areas. For instance, the combined contributions from the literature on citizenship, independent living and governance revealed the ways that societal value systems are socially constructed and, the ways in which interconnections between these three concepts determine access pathways to welfare entitlements and rights. For example, although disabled people have rights to personal assistance in Norway, the societal value system fails to action disabled individual autonomy throughout the personal assistance entitlement process, and the power of resources lies with Norwegian municipalities. Therefore, this study was unique in the examination of the three research questions.

Roulstone and Hwang (2015) brought together the concepts of citizenship, independent living and governance within their analysis which corroborates this study's findings. Similar to this study, their findings supported the conclusion that Centres for Inclusive Living formed collective empowerment bodies for disabled people and that the voices of many disabled people, rather than the voice of one disabled person, are more effective in creating social and political change.

This study also provided valuable methodological insights of disability studies that were examined. For example, the social model of disability (Oliver, 1990) emphasised structural barriers to disabled people's access to independent living and exclude agency, while the post-structuralist perspective (Shakespeare, 1998) failed to identify the agency level factors that lead to change through discourse. However, there is a strong consensus among disability researchers that the overall

objective should be to investigate ways to empower disabled people and improve their rights to independent living.

The journey of constructing the research design contributed towards my learning as a self-identified disabled early career researcher. Oliver and Barnes (2012) are critical of research that is not emancipatory for disabled people. I began with these intentions, but encountered practical limitations. A full co-production approach, for instance, would have involved the need for considerably more time and resources than were available. This direction would have also restricted the opportunity to conduct international comparative research. However, the act of participants sharing their opinions may have encouraged personal reflections on access to independent living and consequently, this study may have benefited people indirectly.

The process of capturing an in-depth contextual understanding of policies, everyday practices and individual emotional responses to lived experiences of disablement in Scotland and Norway was complex throughout this research. The methodological approach lent itself towards an integration of a theory of impairment (Abberley, 1987; Goodley, 2011) with a theory of disability (Oliver, 1990). Consequently, this study drew upon Thomas' (1999) social relational model of disability. Analysis of the data in line with Thomas' social relational model showed structural barriers, such as policies or psycho-social impairment effects throughout lived experiences of disablement.

As Shakespeare (2004) remarked, few studies have adopted the social relational model of disability. This study sought to address this knowledge gap and to enhance the social relational approach using meso governance analysis (Lowe, 2004). For instance, Lowe (2004) outlined that meso analysis acted as a gateway to the exploration of interactions with macro (national) policy making, laterally with other meso level organisations and with micro (agency) level lived experiences and individual action.

The findings from this study uncovered the interconnections across the different tiers of governance within Scotland and Norway, which revealed state assumptions surrounding disabled people's civic engagement, as well as the relationships

between rights and access to specific areas of independent living. For instance, the data showed that independent living in Scotland and Norway is affected by what Hvinden and Halvorsen (2003) describe as regulatory and distributive policies at a macro level. Participants' lived experiences highlighted the interplay between policies and informal and formal forms of governance that facilitated access to independent living. The citizenship outcomes for participants were significantly influenced by macro citizenship parameters, such as Scotland's characteristic nature as a liberal regime and Norway's as a social-democratic regime in accordance with Esping-Andersen's (1990) welfare typologies.

One of the main findings from this study was that peer support acted as a core element throughout the other areas of life for participants. The social relational model (Thomas, 1999), integrated with the meso governance analysis (Lowe, 2004), highlighted the connections for peer support across the societal tiers of governance. For example, policy making in Scotland had started to recognise the merits of a co-production approach that draws upon the collective experiences and perspectives of disabled citizens. Peer counselling emerged as a meso level practice performed by many of the case study organisations employees. This provided a shared frame of reference with disabled service users and created conditions that fostered personal development within individuals. At a micro level, participants reported that peer support assisted with the exploration of the disabled self. For instance, when some participants encountered inclusive environments and practices they did not feel it necessary to identify as a disabled person.

## 8.2 The Implications for Centres for Inclusive Living

The following section outlines the potential implications that this study's findings pose for Centres for Inclusive Living. The participants' narratives and the responses from the online survey respondents addressed the second research question: in what ways do the governance structures of Centres for Inclusive Living enhance disabled people's access to independent living within societies? The findings highlighted the merits of combining the social relational model of disability (Thomas, 1999) and meso level governance analysis (Lowe, 2004). Data analysis distinguished key meso facilitators that enhanced the governance structures for

Centres for Inclusive Living to assist disabled people to access independent living. These meso facilitators were empowerment, peer support and user led governance. Taking each of these facilitators in turn, consideration will be made in relation to the future practical or strategical approaches that may enhance the governance structures around Centres for Inclusive Living, in order to improve disabled people's access to independent living support and services.

As outlined in chapter 2 (the literature review), writing within disability studies Carol Thomas supports a social relation model of disability (Thomas, 1999). The social relational model provides analysis of disablement in terms of macro (national) structural barriers and micro psycho-social lived experiences of disabled people. However, the social relational model fails to acknowledge the impact of organisational governance at a meso level, especially in relation to user led disability related bodies and their impact upon disabled peoples' access to independent living. From the field of housing studies, Lowe (2004) meso governance analysis examines the interconnections between relationships and practices spanning micro (individual), meso (organisational) and macro (national policy) levels of society. The macro and micro focus correspond with the social relational model of disability as well as providing additional theoretical insight into disablement at a meso (organisational) level.

A potential criticism of Lowe's theorising concerns the boundaries between macro, meso and micro societal levels. These boundaries are not always clear cut as demonstrated by some research participants' narratives. For example, in Scotland, senior GCIL manager Chris, described the introduction of a housing information service to GCIL based upon multiple micro level reports of challenges surrounding disabled people accessing suitable housing (see Chapter 5). In 2010 housing providers were encouraged to build 10% of new developments as fully accessible (Scottish Government, 2010), however evidence does not exist to support that this change at the macro level was directly linked either to meso level pressure from GCIL or campaigns by disabled individuals.

The methodological approach by this research focused upon organisational case studies of two Centres for Inclusive Living: GCIL in Scotland and Uloba in Norway.

Chapter 3, The Research Journey, outlines that these two organisational case studies were chosen due to their unique status as user led bodies, run by disabled people to design and provide services for disabled people. Placing data analysis firmly at a meso level enabled the examination of disablement to reveal the ways that Centres for Inclusive Living, using Walmsley (2000) description of disability voluntary organisations, act as buffers between micro lived experiences and macro national policy making. Research participants highlighted that GCIL and Uloba channel collectives of individual lived experiences of disablement at a micro level and facilitate a coherent expression of empowerment to be presented through organisational representatives throughout the macro policy decision making arena. In order that the case studies perform effectively as buffers between the micro and macro levels of society, the organisations rely upon efficient meso user led governance frameworks that ensure that organisational user engagement mechanisms provide opportunities for lived experiences/views from diverse impairment groups to be integrated in decision making processes. An empowering user led governance framework should in essence facilitate a cohesive macro policy campaign informed by the micro lived experiences from locomotional, sensory and cognitive impairment groups.

The findings from this study may help to develop meso level facilitators that enhance disabled people's access to independent living in all types of welfare regimes. Further social enquiry is required to examine whether divergent or convergent meso facilitators exist within different welfare regime types to those of Scotland and Norway, for example within a corporatist regime (Esping-Andersen, 1990). Such enquiry would corroborate or challenge this research data, which forms a snapshot of a specific time and place. Additionally, such research would strengthen the international evidence base especially around the role of Centres for Inclusive Living. This might be welcomed since, as Rummery and Fine (2012) point out, nuanced examinations of policies and practices are sparse.

The first meso facilitator identified by this study was empowerment. In line with the first research question, research participants' narratives of empowerment supported the literature that highlighted the need for a coordinated policy approach towards all of the 12 Pillars of Independent Living in Scotland and Norway in order

to facilitate disabled people's access to independent living. Despite positive policy change in Scotland and Norway, disabled people still lack rights to all areas of life. However, the effective implementation of policies that adhere to the independent living ethos requires simultaneous support across macro (national), meso (organisational) and micro (agency) tiers of society. For example, research participants identified scope in both countries for Centres for Inclusive Living to be included within a co-production policy-making approach in the future, so that disabled people's lived experiences and perspectives shape disabled people's citizenship outcomes.

In both countries, a coordinated approach at a macro level would require the availability of appropriate resources at a meso level. The GCIL participants shared long-term concerns and challenges surrounding service provision due to the lack of security of funding, whilst Uloba participants indicated that a focus on personal assistance ensured viability since no other areas of independent living were financed to the same degree by the Norwegian state. As Beckett (2006) asserted, an effective coordinated policy approach towards independent living with adequate resources and education would need the acceptance of personhood. This would entail the recognition by national governments that citizenship is contingent upon human vulnerability. There may be greater scope in Norway for research to map out a strategic approach towards resourcing all of the 12 Pillars of Independent Living since the social democratic model lends itself to public support for higher taxes (Andersson, 2000). Similar research in Scotland may encounter long-term challenges of implementation in practice.

Since the fieldwork in 2012, Scotland has experienced a lot of political debate and change in light of the referendum on independence in 2014. Part of this discussion held up Norway's social-democratic welfare model, defined by Esping-Andersen (1990), as an exemplar of high living standards and positive action towards equalities (Nordic Horizon, 2015). Although Esping-Andersen's theorising can be viewed as being out dated, recent studies, such as Benjaminsen and Andrades (2015), highlight that comparative research still finds the three welfare models to provide analytical frameworks that can uncover the socio-economic circumstances of particular countries. Esping-Andersen's typology enables the ability to track,

assess and explain the certain spread or varieties associated with specific conditions under scrutiny. Esping-Andersen's typology has also prompted theoretical developments in the area of comparative research. In addition to his three welfare models, a Southern European Welfare model, sometimes referred to as the 'Mediterranean Welfare Regime' has been suggested whereby the role of the family and rudimentary social benefit systems characterise the nature of welfare (Leibfried, 1992; O'Sullivan, 2010). Extension of the European Union to encompass the post-socialist countries of Central and Eastern Europe has led to debates concerning their integration into the welfare typology (Draxler and Van Vliet, 2010).

In 2013, the election of a centre-right coalition government in Norway supported the view held by authors, such as Skeie (2004) and Hanssen et al. (2001) who argue that a neo-liberal regime characterise current Norwegian society and evidence a shift away from Esping-Andersen's Nordic welfare assessment. Contrastingly, Castles (2004) points out that Norway's imbedded social-democratic cultural values and institutions meant that a significant erosion is required over many years before the country exhibits a distinct neo-liberal welfare regime. In line with Castle's assertion, Esping-Andersen's welfare (1990) typology remains relevant for Norway and comparative research analysis.

Additionally the organisational case study of Uloba highlights that in the area of personal assistance, a neo-liberal approach can be utilised to improve disabled access to independent living. For instance, Uloba's personal assistance service delivery model challenges the paternalistic provision of care by the State that excluded disabled peoples' voices and, actively encouraged quality of care (towards Uloba co-owners and their personal assistants) by competing with private personal assistance agencies that ascribe to the medical model of disability (Oliver, 1990).

In line with the first research question, participants in this study highlighted that disabled people in Scotland and Norway encountered similar impediments to independent living and that neither Scotland nor Norway provide rights to all of the 12 Pillars of Independent Living. For example, a shared impediment was the lack

of accessible housing. Although, Norway exhibits stronger macro policy support for mandatory universal design that would benefit Scotland. Scotland meanwhile has Home2Fit, a national accessible housing register that would also potentially benefit Norwegian disabled house seekers if replicated.

The second meso facilitator identified by research participants was peer support. The data indicated that peer support acts as a foundation for other areas of independent living, namely accessible housing and personal assistance. In order to generalise the foundational role of peer support across all of the 12 Pillars of Independent Living, further examination of its role in areas such as education, employment and accessible public transport is needed.

The third research question focused upon whether the nature of self-identification affects disabled people's experiences of and access to independent living. The data highlighted peer support as a meso facilitator where participants' narratives explored tensions around the notion of the disabled self. Participants in both countries reported that peer support, informal or formal forms had increased their contact with their Centre for Inclusive Living. This contact had developed self-awareness of being a disabled citizen who should have rights and access to all areas of life. Centres for Inclusive Living played a key role in the enhancement of participants' access to independent living.

Moreover, Centres for Inclusive Living may benefit from finding out to what extent peer support is utilised by disabled people who are not in contact with these organisations. This information may highlight additional forms of peer support or useful strategies that could be adopted by Centres for Inclusive Living to enhance potential users' access to services. Future research could map out the contact pathways used by users of Centres for Inclusive Living. For example, Pearson and Trevisan (2015) note that the social media environment provides new peer support opportunities. These opportunities may act as substitutions for the lack of peer support experienced through large institutional care facilities where many of the case study organisations founders first engaged with peer support.

The third meso facilitator identified was user led governance. In response to the second research question, user led governance was a unique characteristic of

Centres for Inclusive Living that enhanced disabled people's access to independent living. Both GCIL and Uloba encountered circumstances whereby the majority or all of their services were national in nature. This presents challenges for recognising or responding to localised needs. Scotland and Norway could benefit from feasibility studies into the provision of Centres for Inclusive Living across specific localities or geographical areas. This would assist to identify whether a particular dispersal of independent living service provision increases current efficiency and improves the lived experiences of disablement in both countries. For instance, Scotland has a patchwork of Centres for Inclusive Living organisations, while Norway relies upon Uloba, which, according to participants, originally aimed for the development of satellite Centres for Inclusive Living across different municipalities. The feasibility studies should be financially and strategically supported by national policy makers in order to embody an independent living ethos and recognise disabled people's rights to all areas of life. Additionally, if the outcome of the feasibility studies indicates that independent living service provision would be more effective and efficient if delivered through a greater number of Centres for Inclusive Living, such an approach would require financial and strategic support from the Scottish and Norwegian states.

## 8.3 Future Research and Practice

To summarise, this study closes with key points that would enhance future research and practices in the area of independent living. These key points have been formulated from the research findings. Each point aims to stimulate social enquiry to enhance disabled people's access to independent living in Scotland and Norway.

This study has demonstrated the contributions towards our understandings of disabled people's citizenship and access to independent living through comparative research. The aim is to stimulate and strengthen the international evidence-base around disabled people's access to independent living through the examination of meso facilitators present in different types of welfare regimes. An advantage of this research data analysis was the integration of the social model of disability (Thomas, 1999) and meso level governance analysis (Lowe, 2004).

Although there are various useful methodological approaches within disability research, the findings illustrate the insights across governance tiers that can be gained from a social model and meso governance integration. These insights can be used to design national policy maps to embed the ethos of independent living which is supported by strategic and financial action implementation plans.

One area in particular that was highlighted by this study for potential further social enquiry involves the evaluation of policies in relation to the independent living ethos. In Scotland, for example, co-production has started to be recognised. However, the data from this study suggests that a coordinated policy approach is required across all of the 12 Pillars of Independent Living in Scotland and Norway, and that disabled people's citizenship outcomes would benefit from such a future strategy.

As noted earlier in the chapter, a significant contribution to this research was exploring the role of peer support. According to participants, peer support acted as a core element for other areas of life, in this case accessible housing and personal assistance. Future research could improve our understanding of the relationships between the 12 Pillars of Independent Living if the connections among the remaining 9 pillars are explored in relation to peer support.

The organisational case studies of GCIL and Uloba showed that Centres for Inclusive Living place peer support at the heart of their operations. Peer support took informal and formal forms. However, a useful avenue for further examination is into the peer support networks utilised by disabled people without contact with Centres for Inclusive Living. This may highlight additional or alternative forms of peer support that enhance disabled people's access to independent living.

Both organisational case studies highlighted challenges to effective local delivery of independent living support and services. These challenges included funding constraints and local governance resistance to user led organisations. Both countries would benefit from feasibility studies that establish the number of Centres for Inclusive Living that would enable the most effective delivery of localised services. Within this investigation, the role of monitoring performance and development of user led organisations should also be included. For instance, the

feasibility studies could look at whether an independent user led body could support, monitor and coordinate collaboration between the Centres for Inclusive Living across the country.

Overall, this research has provided methodological and empirical insights into the area of disabled people's access to independent living in Scotland and Norway. The meso level analysis highlighted the essential role that Centres for Inclusive Living play as facilitators for independent living across macro, meso and micro tiers of society. The data revealed the unique techniques of empowerment, peer support and user led governance that enable Centres for Inclusive Living to respond to the needs of disabled people's citizenship outcomes. GCIL and Uloba embody the progress that has been made in both countries during the past thirty years towards disabled people's rights to all 12 Pillars of Independent Living. However, this study presented existing challenges. The persistence and determination of the case study organisational staff, as well as the individual disabled service users provide inspiration for future change through disability research and practices that will continue to enhance independent living for all.

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# Appendix I

*Research Information Sheet*

Hello

My name is Dianne and I'm a 2<sup>nd</sup> year PhD student at the University of Stirling, Scotland. The title of my research is: "A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled peoples' life choices". The aims are:

- To uncover the lived experiences of disablement in Scotland and Norway, with particular reference to housing, independent living and citizenship;

- To highlight the role of housing and its interconnections within the tapestry of welfare systems, governance structures and concepts of citizenship, specifically for disabled people; and

- To identify whether there exists, in either country, a set of practices or mechanisms that impact upon governance structures, facilitating or impeding disabled people's access to independent living.

As a self-defined disabled individual, I have always been drawn to issues around disability, accessible housing, service-user involvement and empowerment. Thus, my goal is to carry out an emancipatory piece of research that is relevant to policy and practice. I hope that it will be of interest to a wide-ranging and diverse audience, providing valuable insights, deepening our understanding of disability issues and actively stimulating future debates and dialogue around disabled people's access to independent living.

My study is a comparative exploration into disabled people's access to independent living in Scotland and Norway. The hope is that the methodology will comprise three parts: interviews with key experts from the fields of disability, housing, governance or citizenship in Scotland and Norway; comparative case studies of the Glasgow Centre for Inclusive Living and Uloba Centre for Independent Living in Drammen; and an electronic survey in Norway and Scotland of agencies, bodies or institutions that work with the centres for independent living, or whose work generally relates to disabled people's access to independent living.

If you would like any further information about my research, please do not hesitate to contact me on 07920480422 or either of my PhD supervisors, who would also be able to assist:

| Professor Isobel Anderson | Professor Kirstein Rummery |
|---|---|
| Room 3S11 | Room 4S28 |
| University of Stirling | University of Stirling |
| FK9 4LA | FK9 4LA |
| Direct Tel: 01786 467718 | Direct Tel: 01786 467693 |
| E-Mail: | Email: |
| Isobel.anderson@stir.ac.uk | Kirstein.rummery@stir.ac.uk |

I am very much looking forward to speaking with you.


Yours sincerely


Dianne-Dominique Theakstone.

# Appendix II

*Email To Ascertain Case Study Consent*

Dianne-Dominique Theakstone

PhD student in Applied Social Sciences

Room 4S35

The University of Stirling

FK9 4LA

Tel: 01786 476171

Mobile: 07920480422

E-Mail: ddt5@stir.ac.uk


Dear --- (name of Chief Executive/Director)

Thank you very much for expressing your interest in my PhD research entitled "A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices" during our recent conversation on the phone.

I'm writing to seek consent from GCIL/Uloba in relation to my PhD research. I'm currently a 2nd year PhD student at the University of Stirling, Scotland, and I have attained ethical approval from the University of Stirling Ethics Board to commence field work. My study is a comparative exploration of disabled people's access to independent living in Scotland and Norway.

As part of the research design, I would very much like to conduct a case study of GCIL/Uloba. This would entail face-to-face, semi-structured interviews with a member of staff from each hierarchical level or service/project of the organisation. The overall objectives are:

To examine the origins of the organisation, its overall aims and critically assesses these against its outcomes;
To outline monitoring mechanisms deployed for each service or project;

To examine to what extent service-user involvement is utilised throughout organisational decision-making;

To examine the organisation's role within the respective country's policy-making process;

To highlight relationships with other agencies or bodies and examples of joint-working; and

To explore the motivational and personal backgrounds of the staff/volunteers.

I would also appreciate any assistance you could provide regarding seeking potential research participants who are/have been service-users of the organisation, but who are not in the organisation's employment. This could be an advert in your newsletter or an email circulated on my behalf. I feel that it is important that I do not approach them directly to avoid unintentional pressure or coercion. It will be entirely their choice to contact me if they would be interested in being a potential participant. A £10 shopping voucher will be given to participants as a token of appreciation and, as the researcher, I will pay for any travel or support costs incurred through their participation.

Throughout this research case study, anonymity for GCIL/Uloba will be challenging. There are very few Centres for Independent Living – two in Scotland and one in Norway. Reference of vague organisational job roles may result in others, especially within the organisation, being able to discern an individual's identity. The content presented in the final PhD thesis would assist with anonymity for public consumption as participants would be assigned a fictitious name. Therefore, every potential research participant will be informed of the potential lack of anonymity and it will be their choice whether to take part. Attached are my research instruments for your perusal, which will be sent to potential participants. There are the Consent, Anonymity, Recording and Use of Data sheets, interview/focus group schedules, a copy of the confirmation/general information email and the advert aimed at recruiting disabled service-users who are not

employed by your organisation. If you require further clarification regarding any issues, please do not hesitate to contact me.

I would be extremely grateful if you could consider my request for consent to conduct the case study of GCIL/Uloba. I have undergone a CRB check, which is required for working with vulnerable groups and includes disabled people. The study has also clear protocols that adhere to the UK (1998) Data Protection Act and (2000) Act relating to the processing of personal data in Norway.

Please do not hesitate to contact me if I would be required to submit further information for your perusal or for the attention of GCIL´s/Uloba's committee board.

If you have any queries or complaints concerning my research at any time, please feel free to contact me on 07920480422/email ddt5@stir.ac.uk, or my PhD supervisors, who will be able to assist you:

| Professor Isobel Anderson | Professor Kirstein Rummery |
|---|---|
| Room 3S11 | Room 4S |
| University of Stirling | University of Stirling |
| FK9 4LA | FK9 4LA |
| Direct Tel: 01786 467718 | Direct Tel: 01786 467693 |
| E-Mail: Isobel.Anderson@stir.ac.uk | Email: Kirstein.Rummery@stir.ac.uk |

Thank you very much for your time.

Yours sincerely

Dianne-Dominique Theakstone

# Appendix III

***Cover Email: Key Experts***

Dianne-Dominique Theakstone

PhD student in Applied Social Sciences

Room 4S35

The University of Stirling

FK9 4LA

Tel: 01786 476171

Mobile: 07920480422

E-Mail: ddt5@stir.ac.uk

Thank you for your interest in my PhD research and for giving me the opportunity to invite you to take part in a 1-to-1 interview telephone interview. It should last approximately 1 hour.

As I explained during our recent phone conversation, my name is Dianne and I'm a 2nd year PhD student at the University of Stirling, Scotland. The title of my research is: "A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled peoples' life choices". The aims are:

- To uncover the lived experiences of disablement in Scotland and Norway, with particular reference to housing, independent living and citizenship;

To highlight the role of housing and its interconnections within the tapestry of welfare systems, governance structures and concepts of citizenship specifically for disabled people; and

- To identify whether there exists, in either country, a set of practices or mechanisms that impact upon governance structures, facilitating or impeding disabled people's access to independent living. As a self-defined disabled individual, I have always been drawn to issues around disability, accessible housing, service-user involvement and empowerment. Thus, my goal is to carry out an emancipatory piece of research that is relevant to policy and practice. I hope that it will be of interest to a wide-ranging and diverse audience, providing valuable insights, deepening our understanding of disability issues and actively stimulating future debates and dialogue around disabled people's access to independent living.

My study is a comparative exploration into disabled people's access to independent living in Norway and Scotland. It has three parts: interviews with key experts from the fields of disability, housing, governance or citizenship in Scotland and Norway; comparative case studies of the Glasgow Centre for Inclusive Living and Uloba Centre for Independent Living in Drammen; and an electronic survey in Norway and Scotland of agencies, bodies or institutions that work with the Centres for Independent Living or whose work generally relates to disabled people's access to independent living.

I would like to confirm that we arranged to speak on (day) the (date) (month) at (time). Please find attached the questions that will guide our conversation. You can withdraw at any time, and do not have to answer all of these questions.

I will shortly send you a follow up email, which will contain further information concerning consent, anonymity, recording and the use of data. Meanwhile, if you would like any further information about my research, please do not hesitate to contact me on 07920480422, or either of my PhD supervisors, who would also be able to assist:

| Professor Isobel Anderson | Professor Kirstein Rummery |
|---|---|
| Room 3S11 | Room 4S |

| University of Stirling | University of Stirling |
|---|---|
| FK9 4LA | FK9 4LA |
| Direct Tel: 01786 467718 | Direct Tel: 01786 467693 |
| E-Mail: Isobel.Anderson@stir.ac.uk | Email: Kirstein.Rummery@stir.ac.uk |

I am very much looking forward to speaking with you.

Yours sincerely

Dianne-Dominique Theakstone

# Appendix IV

***Electronic Survey Cover Email***

A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices.

INTRODUCTION

Dear participant

Thank you for your interest in my PhD research "A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices".

I would like to invite you to participate in an online survey that contains ten questions. It should take approximately ten minutes to complete and can be accessed via the link provided within the covering email. The closing date for the online survey is the 31st May 2012. Please be aware that you can withdraw at any time, pass on answering any questions and that you should not feel obliged to take part at all. Responses will be confidential, as long as you do not disclose behaviour that breaks the law. In such cases, I would be legally obliged to inform my PhD supervisors. If you have comments or complaints concerning my research, at any stage, please do not hesitate to contact me or either of my PhD supervisors.

Outlined below is further information concerning consent, anonymity, recording and the use of the research data.

CONSENT

In order to participate in this study, it is important that you do so through your own choice and without any sense of coercion. At the beginning of the survey, you are required to tick a box to confirm your consent to participate. Only then will you be able to continue onto the survey questions. You can withdraw at any time during the study. If you experience emotional distress at any point, please bring this to my attention immediately. I will, in such situations, contact my PhD supervisor Isobel Anderson (contact details below) for advice, and provide local helpline numbers where you could find support.

ANONYMITY

At the start of the survey, you will be asked about whether you would like anonymity. Your responses can be anonymised, and any reference to your comments or views will be under a pseudonym in the PhD thesis. However, you may wish to disclose comments, views or experiences as a representative of your organisation or institution.

RECORDING OF DATA

Survey responses can only be accessed by me, as the researcher. For analysis, data will be transferred onto my university computer, which is password protected and situated in a keypad secured office.

As this PhD is funded by the Economic and Social Research Council, data will be submitted to their archive. I will also ask for your consent at the beginning of the session, concerning the potential future use of this data. I would very much like to conduct a post doctoral follow-up study, which may, for instance, go on to examine other countries. Therefore, I would be seeking consent from you to retain your data, approach you in the future and to confirm consent before embarking upon any future study.

If you have any queries at all, please do not hesitate to contact me on: 07920480422/email ddt5@stir.ac.uk

Thank you very much for your time.

Yours sincerely


Dianne-Dominique Theakstone

# Appendix V

*CONSENT, ANONYMITY, RECORDING AND DATA USE*

Dear (name of potential research participant)

Thank you for your interest in my PhD research "A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices".

During our face-to-face chat, which will last approximately an hour, please be aware that you can withdraw at any time, pass on answering any questions and that you should not feel obliged to take part at all. Responses will be confidential as long as you do not disclose behaviour that breaks the law. In such cases, I would be legally obliged to inform my PhD supervisors. If you have comments or complaints concerning my research at any stage, please do not hesitate to contact me or either of my PhD supervisors.

Outlined below is further information concerning consent, anonymity, recording and the use of the research data.

## CONSENT

In order to participate in this study, it is important that you do so through your own choice and without any sense of coercion. You can withdraw at any time during the study. *Norway only* Please be aware that, if requested, I will be accompanied by a Norwegian translator during our session.

You do not have to answer all or any of the questions; neither do you have to discuss all of the topics. For example, I inquire about personal circumstances and views that you may find too sensitive to disclose. If you experience emotional distress at any point, please bring this to my attention immediately. I will, in such situations, contact my PhD supervisor Isobel Anderson (contact details below) for advice and support.

At the beginning of the session, I will also confirm your consent to participate. This will be done verbally. The use of a sound recorder will enable me to keep a record of your consent and make the process accessible for me or research participants who cannot write or read print. However, if you would prefer to sign a printed

consent research agreement, please let me know prior to us meeting and this will be made available. A transcript of our conversation will be made available for you to check, verify and give any feedback upon. There may be issues, responses or phrases you would rather were omitted.

**ANONYMITY**

Your responses will be anonymised and any reference to your comments or views will be under a pseudonym in the PhD thesis. As I enlisted the assistance of GCIL/Uloba to circulate an advertisement and email, it may be possible that they will identify your contribution. If you have any concerns about anonymity, you can withdraw from the study at any stage, or pass on answering any questions.

**RECORDING OF DATA**

The session will be recorded using an Olympus digital sound recorder. This will enable me, as the researcher, to concentrate upon your responses, transcribe sessions for data analysis and keep an audio record of consent and anonymity. Your consent will be verbally sought at the start. The data will be transferred onto my university computer, which is password protected and situated in a keypad secured office. Audio files on the digital recorder will then be deleted. Only I, as the researcher, will have access to your audio transcript.

The audio files on my university computer shall be used during data analysis. I will also seek your consent to retain the data for a potential future piece of research. I am very keen to conduct a postdoctoral study that includes more countries. I would not embark upon any such study without confirming consent beforehand.

Thank you once again for your interest and I very much look forward to speaking with you.

Yours sincerely
Dianne-Dominique Theakstone

# Appendix VI

*Electronic Survey Reminder Email*

Dear (name of potential participant)

Thank you for your interest in my PhD study "A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices".

This is an automatic reminder to highlight that there is still time for you to participate, if you have not already done so, in my online survey. It can be accessed via the link at the bottom of this message.

The closing date for contributions is the (Scotland 31st May/Norway 30th June).

If you have any queries at all, please do not hesitate to contact me.

Yours appreciatively

Dianne-Dominique Theakstone

# Appendix VII

*Confirmation of Transcript Email*

Dear (participant's name)

Thank you once again for your contribution to my PhD study; "A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices".

Thank you very much for providing feedback on the transcript. This will now be used during my research data analysis.

As a research participant, you will automatically receive a copy of the key findings from the research once it has been submitted and accepted by the University of Stirling. This is due to occur at the end of 2014.

In the meantime, if you have any queries at all please do not hesitate to contact me.

Yours appreciatively

Dianne-Dominique Theakstone

# Appendix VIII

*Interview Schedule: Key Experts*

A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices.

**Introduction**

The following questions will be used to guide our discussion around disabled people's access to independent living in Scotland/Norway. Please could you read through them carefully before consenting to participate in my study? Could you consider whether you would like your responses to be anonymised within the PhD thesis under your field of expertise? For example, key expert in the field of policy. Anonymity will be maintained to the best of my ability. Or, would you prefer others to know your identity?

You will receive a follow-up email shortly containing a sheet entitled Consent, Anonymity, Recording and Use of Data. Please could you read through this sheet carefully too.

Please do not hesitate to contact me with any queries. You can withdraw from the study at any stage and choose to leave out any of the questions.

Thank you very much for your time

Dianne-Dominique Theakstone


1. Can you tell me your job title and what your role involves?

2. Can you describe your background prior to taking up your role as (insert job title) such as educational/employment/campaigning/political involvement?

3a.  Do you self-identify as disabled? If so, in what ways?

3b. Are you defined as disabled by society? If so, in what ways?

3c. Do you have any type of impairment?

4. In your field, what policies or research address disabled people's access to independent living?

5a. In your opinion, are there any practices or policies that facilitate disabled people's access to independent living in Scotland?

5b. In your opinion, are there any practices or policies that impede disabled people's access to independent living?

6. To what extent do you feel disabled people as service-users actively shape policies in (Scotland/Norway)?

7. Do you have a view on the role that Centres for Independent Living play within society and the policy-making process?

8. In your opinion, do Centres for Independent Living empower disabled people? Please could you explain your response?

9. Are there any aspects or areas relating to disabled people's access to independent living that you feel --- (GCIL/Uloba) does not address at the moment?

10a. What do you consider should be key future ambitions, policies or practical solutions towards disabled people's access to independent living?

10b. Do you have any future personal aspirations around disabled people and independent living?

# Appendix IX

*Interview Schedule: Organisation Case Studies*

A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices.

## Introduction

The following questions will be used to guide our discussion around disabled people's access to independent living in Scotland/Norway. Please could you read through them carefully before consenting to participate in my study? As anonymity will be challenging, could you consider whether you are willing for all of your responses to be read by others, or whether there are specific questions, such as around personal background, you would rather leave out?

You will shortly receive a follow-up email containing a sheet entitled Consent, Anonymity and Recording and Use of Data. Please could you read through this sheet carefully too.

Please do not hesitate to contact me with any queries. You can withdraw from the study at any stage and choose to leave out any of the questions.

Thank you very much for your time

Dianne-Dominique Theakstone


Questions


1. Can you describe your role within the organisation?

2a. How did you become involved with the organisation?

2b. Can you describe your background prior to taking up your role within the organisation such as educational/employment/campaigning/political involvement?

3a. Do you self-identify as disabled? If so, in what ways?
3b. Are you defined as disabled by society? If so, in what ways?

3c. Do you have any type of impairment?

4a. Can you outline the services and projects that GCIL operates or is involved with?

4b. Which external agencies, institutions or bodies have you experienced good working relations with?

5. In general, is there an overarching framework GCIL uses to monitor and assess outcomes and performance?

6. In what ways does GCIL empower disabled people?

7a. To what extent does the organisation incorporate service-user involvement throughout its decision-making process?

7b. Are you aware of any strengths or weaknesses in this structure?

8. Are there any aspects or areas relating to disabled people's access to independent living that you feel GCIL does not address at the moment?

9a. To what extent do Centres for Independent Living in Scotland participate in, or influence, policy making at national, UK and European levels?

9b. Are there any strengths? Are there any areas for future improvement?

10a. In your opinion, are there any practices or policies that facilitate disabled people's access to independent living in Scotland?

10b. In your opinion, are there any practices or policies that impede disabled people's access to independent living?

11. What are the future aspirations of GCIL?

12. Do you have any future personal aspirations around disabled people and independent living?

# Appendix X

*Service User/co-owners Interview Schedule*

A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices.

**Introduction**

The following questions will be used to guide our discussion around disabled people's access to independent living in Scotland. Please could you read through them carefully before consenting to participate in my study. Your responses will be anonymised to the best of my ability during the write up of my thesis. For example, your comments will appear under a pseudonym.

Accompanying this interview schedule is a sheet entitled Consent, Anonymity, Recording and Use of Data. Please could you read through this sheet carefully too before participating in the study.

Please do not hesitate to contact me with any queries. You can withdraw from the study at any stage and choose to leave out any of the questions.

Thank you very much for your time.

Dianne-Dominique Theakstone


Questions


1a. Can you tell me in what way you have been involved with the Glasgow Centre for Inclusive Living?

1b. How did you find out about the organisation?

2. Can you tell me about your background, such as educational/employment/campaigning/political involvement?

3a. Do you self-identify as disabled? If so, in what ways?
3b. Are you defined as disabled by society? If so, in what ways?

3c. Do you have any type of impairment?

4a. In your opinion, are there any practices or policies that facilitate disabled people's access to independent living in Scotland?

4b. In your opinion, are there any practices or policies which impede disabled people's access to independent living?

5. To what extent do you feel disabled people as service-users actively shape policies in Scotland?

6. Do you have a view on the role that Centres for Independent Living play within society and within the policy-making process?

7. In your opinion, do Centres for Independent Living currently empower disabled people? Please could you explain your response?

8. Are there any aspects or areas relating to disabled people's access to independent living which you feel the Glasgow Centre for Inclusive Living in Scotland does not address at the moment?

9a. To what extent do you feel the Glasgow Centre for Inclusive Living involves service-users during its decision-making process?

9b. Are you aware of any strengths or weaknesses in this structure?

10a. What do you consider should be key future ambitions, policies or practical solutions towards disabled people's access to independent living?

10b. Do you have any future personal aspirations around accessing independent living, or perhaps in relation to assisting other disabled people to access independent living?

# Appendix XI

*Advert for Newsletter/Circulatory Email*

POTENTIAL SERVICE-USER RESEARCH PARTICIPANTS

A citizenship of humanity: a comparative analysis of the governance mechanisms in two centres for independent living that enhance disabled people's life choices.

Hello

My name is Dianne and I'm a 2nd year PhD student at the University of Stirling, Scotland. I am conducting a comparative study that is examining disabled people's access to independent living in Scotland and Norway.

As part of the research, I would very much like to chat to individuals who have used/are using a service or are involved with a project at GCIL/Uloba. I am very interested to hear about your experiences of the organisation, both positive and not so positive, and your opinion on how disabled people's access to independent living should be addressed in general within your country.

Participation would involve a face-to-face chat with me as the researcher for approximately an hour. *__Norway__* I will be accompanied by a Norwegian translator to assist with communication. We can meet in a private venue where you feel safe and comfortable. Participants will receive a £10 shopping voucher as sign of my appreciation and I will pay for any travel or personal support costs you incur in order to take part.

If you would like further information about taking part, please call me on: 07920480422 or email me directly at: ddt5@stir.ac.uk.

Thank you very much for your time


Dianne-Dominique Theakstone

# Appendix XII

*ONLINE SURVEY*

Have you read the consent?

Yes ☐   No ☐

1.Would you like your responses to be anonmyised?

Yes ☐   No ☐

2. What is your job title?

-----------------------------------------------------------------------------

3. What is your organisation's name?

--------------------------------------------------------------------------------

4. What gender are you?

---------------------------------------------------------------------------------

5.  What age are you?

 18-24 ☐   25-34 ☐ 35-44 ☐ 45-54 ☐ 55-64 ☐ 65 plus ☐

6a.  Do you self identify as disabled?

Yes ☐   No ☐

6b. If yes, could you please explain your answer?

---------------------------------------------------------------------------------------

7a. Do you have any type of impariment?

Yes ☐   No ☐

7b. If yes, could you please explain your answer.

--------------------------------------------------------------------------------

8. Can you descirbe what your organisation does and its overall objectives?

9. In what ways does your orgnaisation play a role in disabled people's access to independent living?

--------------------------------------------------------------------------------

10a. Are there any policies or practice that you feel faciliate disabled people's access to independent living?

Yes ☐   No ☐

10b.  Please explain your answer?

--------------------------------------------------------------------------------

11a. Are there policies or practices which impede disabled people's access to independent living?

Yes ☐   No ☐

11b. Please explain your answer.

--------------------------------------------------------------------------------

12. To what extent do you feel disabled people as service-users shape policies in Scotland?

Not at all ☐   A little ☐   A lot ☐   Completely ☐   I do not know ☐

13. What are your views around the role that Centres for Independent Living play in the policy making process?

-------------------------------------------------------------------------------------

14. To what extent is your organisation involved with the GCIL?

Not at all ☐    A little ☐      A lot ☐     Completely ☐     I do not know ☐

15. If your organisation has been involved with the GCIL, could you describe any beneficial aspects or outcomes?

-------------------------------------------------------------------------------------

16a. Are there any aspects or issues relating to disabled people's access to independent living which you feel the GCIL does not address at the moment?

Yes ☐        No ☐        I don't know ☐

16b. If yes, please explain your answer?

-------------------------------------------------------------------------------------

17. Please describe what you think should be key future ambitions, policies or practical solutions towards disabled people's access to independent living in the future?

-------------------------------------------------------------------------------------

18a. Do you have any personal ambition relating to disabled people or independent living?

Yes ☐        No ☐

18b. If yes, please describe?

-------------------------------------------------------------------------------------

If you would like a copy of the research findings, please tick Yes ☐ and leave an email address

-------------------------------------------------------------------------------------

Would you be willing for the researcher to contact you in the future in relation to re-using your data for a potential post doctoral study?

Yes ☐   No ☐

If yes, please leave the best contact details.

# Appendix XIII

*Lifetime Home's Design Criteria*

1. Parking: provide, or enable by cost effective adaption, thus making getting in and out of the vehicle as convenient as possible for the widest range of people (including those with reduced mobility and/or with children).

2. Approach to dwelling from parking: enable convenient movement from between the vehicle and dwelling for the widest range of people (include those with reduced mobility and/or those carrying children or shopping).

3. Approach to all entrances: enable as practicable as possible convenient movement along other approach routes to dwellings.

4. Entrances: enable ease of use for the widest range of people.

5. Communal stairs and lifts: enable access to dwelling above the entrance level to as wide a range of people as possible.

6. Internal doorways and hallways: enable access to internal doors and hallways.

7. Circulation space: enable convenient circulation of as many people as possible.

8. Entrance level socialising space: provide accessible space for visitors less able to use stairs.

9. Potential entrance level bed spaces: provide opportunity for a household member to sleep on the entrance level if they cannot use the stairs.

10. Entrance level WC and shower drainage: provide accessible WC or showering facilities for members of the household or visitors who cannot use the stairs.

11. WC and bathroom walls: ensure future provision of grab rails is possible to assist with independent use of the WC and bathroom facilities.

12. Stair and potential though-floor lift: enable access to the dwelling above the entrance level to the widest range of households.

13. Potential to fit or the fitting of a hoist and for bedroom-bathroom relationship: assist with independent living by providing movement between bedroom and bathroom.

14. Bathrooms: accessible bathroom on every storey where there is a main bedroom.

15. Glazing and window handle heights: in the main living space it should be possible to view out of the window whilst seated and approachable for those with restricted mobility or reach.

16. Location of service controls: locate regularly used service controls or those used for emergencies in places for as wide a range of people as possible, including those with restricted mobility or reach.

Source: Adapted from Lifetime Homes "Quick Print Version (revised criteria), Design Criteria 5 July 2010.